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Under-Served Minority Women

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13. ABSTRACT (Maximum 200 Words) <p><b>Purpose:</b> To describe the components of primary care associated with adherence to regular breast cancer screening among low-income minority women. <b>Scope:</b> This study included secondary analyses of an existing dataset (completed-yr 1), conduction of focus groups (completed yr 2), and the development and conduction of a bilingual population-based telephone survey of lower income women over age 40 in Washington, D.C. to assess their experiences with breast cancer screening and its use in their primary care settings. (yrs 2-3) Preliminary analyses of these data have been included in this annual report. Final analyses will be completed during year four. As described in the 2nd annual report, the PI obtained RO3 funding from NCI to expand the originally proposed survey from a clinic-based convenience sample to a population-based sample from throughout Washington, D.C and to include cervical and colorectal cancer screening in addition to the main focus of breast cancer screening. <b>Major Findings &amp; Results to date:</b> The survey response rate was 86%. Two primary care variables, continuity of care (visit-continuity), and comprehensiveness of services (counseling) were consistently associated with adherence to screening for all cancers. In adjusted analyses, continuity with a usual source of care* and with a usual doctor that one sees at that place* was strongly associated with adherence to clinical breast exams (OR 4.9* &amp; 8.0* p ≤ .01), mammograms (OR 6.4* &amp; 6.4* p ≤ .01), and pap smears (OR 2.8* (NS) &amp; 3.9*, p ≤ .01) with a trend toward higher colorectal cancer screening (OR 5.8* &amp; 4.4*). <b>Significance:</b> Attainment of "optimal" primary care is strongly associated with adherence to breast, cervical and colorectal cancer screening for urban low income women of color. Findings will guide design of a future intervention that emphasizes important features of primary care in order to increase adherence to screening.</p>				
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**TABLE OF CONTENTS**

Cover.....	1
SF 298 .....	2
Table of Contents.....	3
Introduction.....	4
Body.....	5-7
Key Research Accomplishments.....	8-9
Reportable Outcomes .....	10
Conclusions.....	11-12
References (Included in Appendix manuscripts)	
Appendices.....	13-56

## 1. INTRODUCTION

The overall goal of this study is to describe the components of primary care associated with adherence to regular breast cancer screening among low-income minority women. The proposed study pursues this goal by investigating features of the structure and process of primary care structure which are associated with breast cancer screening for minority women via: 1) analysis of an existing data-set of 2,600 multi-ethnic minority persons in New York City (NYC). Building on this, 2.) additional features of primary care delivery systems which promote regular breast cancer screening for under-served minority women were examined in a Washington D.C.-based study. This Washington D.C. based phase included a.) a qualitative component (focus groups) and b.) a quantitative component (survey). Finally, in year four, in conjunction with provider representatives from local primary care clinics, an intervention will be developed to increase regular screening by CBE and mammography that will be implemented in the future under separate funding.

## **2. BODY**

The following is an account of the progress made in the third year toward meeting the objectives specified for the study "Primary Care and Regular Breast Cancer Screening for Under-Served Minority Women," funded by the Department of the Army as a Career Development Award.

### **The Specific Aims of the study are as follows:**

1. To investigate features of the primary care system which are associated with higher rates of breast cancer screening for minority women, using an existing data-set of 2,600 Caribbean-, Haitian- and U.S.-born blacks, and Puerto Rican, Dominican, Colombian, and Ecuadorian Hispanics living in NYC. (Year one-completed)

2. To conduct additional examinations of the features of primary care delivery systems which promote regular breast cancer screening for under-served minority women in four Washington D.C. primary care clinics. (In progress)

a. To conduct a focus group of the D.C. clinic patients and providers about perceived barriers to getting regular screening within their primary care systems. (These focus groups will include members of the advisory boards from the primary care clinics). (Year 1-2 focus groups completed)

b. Using focus group input and preliminary analyses from Aim 1, the PI developed a survey focused on features of primary care systems and regular screening. (Year 2)

c. To administer the survey to a population-based sample of women residing in the lower income areas of Washington, D.C. to assess their experiences with breast cancer screening in primary care.

d. To provide feedback on the survey results to the primary care clinic advisory board representatives. (Year 4)

3. To develop, in conjunction with the provider representatives from the primary care clinics, a primary care intervention to increase regular screening by CBE and mammography which could be implemented in the future under separate funding. (Year 4)

### **Progress Report August 1, 1999-August 1, 2000**

#### **2.1 Revision of protocol during year two (since original application):**

**2.1.1.** Year 3 Focus group: The initial statement of work in the original proposal listed as a deliverable for year three the summary of findings from a second focus group. However, because the PI was able to conduct four rather than just one focus group in years 1-2, and because she obtained adequate saturation of themes from the focus groups (manuscripts summarizing focus group findings were included in both this annual report and in year two annual report), and because the focus group results were presented back to the clinic directors and advisory board members on a one-on-one basis, it was not necessary to convene a focus group in year three.

#### **2.1.2 Change from a clinic-based survey to a population-based telephone survey:**

For several reasons related to the quality of data and research questions, the P.I. and her mentors felt that a population-based telephone survey of women aged over 40 in the District of Columbia's lower income areas would be a preferred approach to the use of in-clinic interviews at just four clinic sites. The reasons and limitations of the new approach have been outlined in the table below:

<b><u>Original Proposal to Dept. of Army</u></b>	<b><u>Enhanced Proposal</u></b>
(In-person interviews at four primary care clinics)	(Population-based telephone survey of lower-income women from throughout Washington, D.C.)
<b>Strengths:</b> May be less threatening to respondent than a phone call  Could more easily include a validation of self-report of screening (Though this was not budgeted for under proposal)	<b>Strengths:</b> Random sample  More representative of all low-income women throughout D.C., not just a convenience sample of users from a few community clinics  Includes non-users and low-users  More efficient sampling strategy  Primary care sites analyzed would not be limited to just four sites
<b>Limitations:</b> On-site clinic interviews may lead to response bias, i.e. women reluctant to say negative things about their care when in the clinic  Results would be less valid, i.e. not as generalizable to low-income women from other sites, or who are low or non-users of clinic services  On-site interviewing was felt to be a burden for the clinic's and their available space  On-site interviewing is less confidential for the respondent than a phone interview in the privacy of their own homes  Much longer time is required to recruit women meeting inclusion criteria for study than in a population-based phone interview	<b>Limitations:</b> Does not capture persons without phones  Validation of self-report of breast cancer screening, should we decide to do it later on, is more difficult since people are from many different primary care sites

**2.2 How the revised protocol was funded:**

In December of 1998, the P.I. submitted an RO3 application to NCI for research costs of the telephone administration phase. This application budgeted for money for contract out just the phone phase of the survey's administration. The budget did not include any request for the P.I.'s salary. There was no budgetary overlap with the Dept. of Army Career Development Award proposal. The P.I. received the funding from NCI and used it to supplement the telephone survey expenses. The P.I. notified her project officer from the Dept. of Army at the time that she applied for the RO3 to be sure that there were no conflicts from the Dept. of Army's perspective. The P.I. was assured that this application to NCI to supplement the research costs of this project was acceptable. All of this was previously reported in the 2<sup>nd</sup> annual report, but is being repeated here to avoid confusion.

**2.3. Survey Administration:** Year 3 focused on the survey piloting, administration, data collection, data cleaning and early analyses. Detailed descriptions of the survey methodology, initial results and preliminary conclusions are summarized in the first draft of a manuscript included in the appendix of the annual report. The draft manuscript is entitled, "Lower income women whose ambulatory care systems contain features of optimal primary care are more likely to adhere to cancer screening recommendations." (It is the first inclusion in the appendix of this annual report.)

**2.4 Implications of project for future study:** Based on survey findings, a primary care intervention to address the specific mutable aspects of primary care as they relate to breast cancer screening will be developed in the future. (This will be the subject of a future proposal) Together, such research has the potential to decrease the disproportionate cancer burden experienced by lower-income Black and Hispanic women. This intervention will be developed in year four of this CDA.

**2.5 Coursework**

The PI had biweekly research meetings with her mentor and attended the Cancer Prevention and Control breast cancer epidemiology and research seminars at Lombardi Cancer Center. She also attended the NCI Cancer Control Academy for the Special Populations Network. The P.I. attended journal club in the Division of Cancer Prevention and Control, Lombardi Cancer Center, Georgetown University. She prepared a presentation for one of the sessions as well on an article on cancer screening.

**2.6 Meetings attended**

- 1. Era of Hope: Atlanta, Georgia June 2000.** Abstract was presented at the poster session.
- 2. American Society of Preventive Oncology- ASPO** attended and abstract accepted, March, 2000 Bethesda, Maryland.
- 3. NCI-Cancer Control Academy**, July, 2000, Pooks Hill Marriott.

## **KEY RESEARCH ACCOMPLISHMENTS**

### **Year One**

- Completed Several analyses of the New York City Multiethnic Data set on Cancer Screening
- Published Paper in the American Journal of Public Health on Acculturation and Breast Cancer Screening in Hispanic Women as a result of one of these analyses of NYC data
- Developed models that to assess features of primary care that were associated with use of CBE and mammography as reported in the first annual report and in the above publication in American Journal of Public Health (submitted in year one annual report)
- Contacted directors of community clinics in Washington D.C. and conducted in-depth interviews of directors as well as visited their clinics
- Conducted four focus groups of Hispanic and African-American Women from four community health clinics in Washington D.C. to probe their experiences with cancer screening and with primary care
- Wrote report summarizing focus group findings (submitted in year one annual report)
- Abstract submitted to the Society of General Internal Medicine's Annual Meeting

### **Year Two**

- Developed survey to collect data from women in Washington, D.C. to obtain their experiences with breast cancer screening, as well as cervical and colorectal cancer screening, in their primary care settings
- Obtained additional funding from NCI in the form of a small research grant (RO3) which will help to pay for the telephone administration of the survey and allow expansion of the survey to include cervical and colorectal cancer in addition to the focus of breast cancer
- Piloted the survey among women meeting inclusion criteria from a community clinic in Washington, D.C.
- Wrote summary report of survey pilot findings (in appendix)
- Began sample identification with the corporation which will generate the phone list of targeted random-digit-dial numbers
- Presented research study on health and cancer information sources used by a multiethnic community in NYC as a result of further analyses of multiethnic data from phase one



- Submitted and had accepted a manuscript resulting from analysis of the NYC multiethnic data on “Health and cancer information sources used in a multiethnic population,” American Journal of Preventive Medicine (in appendix)
- Submitted a manuscript of focus group findings (from year one) to the Journal of Family Practice, which is under review. (in appendix)

### **Year Three**

- Focus group manuscript published. (in appendix)
- Findings from all four focus groups were reported on a one-on-one basis to the clinic directors
- Telephone survey was administered, data collected and initial analyses conducted
- Draft of manuscript summarizing the findings from the survey (1<sup>st</sup> inclusion in appendix)
- P.I. has begun to work on an intervention design for the year four proposal with one of the primary care clinic directors

## REPORTABLE OUTCOMES

### 1. Manuscripts

**O'Malley AS**, Forrest CB, Mandelblatt J. Lower-Income Women's Primary Care and Adherence to Cancer Screening Recommendations. In progress

**O'Malley AS**, Mandelblatt J, Johnson A, Kerner J. "Acculturation and Use of Breast Cancer Screening in Urban Hispanic Women." *American Journal of Public Health*. 1999;89:219-227.

**O'Malley AS**, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. *American Journal of Preventive Medicine*. 1999;17 (3) In press.

**O'Malley AS**, Forrest CB, O'Malley PG. Low Income Women's Priorities for Primary Care. *Journal of Family Practice*. 2000;49:141-146..

Mandelblatt J, Gold K, **O'Malley AS**, Taylor K, Cagney K, Hopkins JS, Kerner J. "Use of Breast and Cervix Cancer Screening by Multi-Ethnic Elderly Women." *Preventive Medicine*. 1999; April 28 (4):418-425.

### 2. Abstracts/ Presentations

**O'Malley AS**, Forrest CB, Mandelblatt J. Primary Care and Regular Breast Cancer Screening. Era of Hope 2<sup>nd</sup> annual meeting, Atlanta Georgia, June 8-12, 2000.

**O'Malley AS**, Forrest CB, Mandelblatt J. Primary Care and Regular Breast Cancer Screening. ASPO, March 2000.

**O'Malley AS**, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. Prevention99: American College of Physician's Annual Meeting.

### 4. Awards

**Best Faculty Poster Award** at the American College of Preventive Medicine's and American Teacher's of Preventive Medicine's annual meeting, *PREVENTION 99*

For: **O'Malley AS**, Kerner J, Johnson L. Are We Getting the Message Out to All? Health Information Sources and Ethnicity. Prevention99: American College of Physician's Annual Meeting.

### 5. Funding Obtained based on Work Supported by this Award

NCI-RO3. August 1999-December 2001. (Principal Investigator) Community-Based Primary Care and Regular Cervical, Colorectal and Breast Cancer Screening in Low-Income Women. (Explained in detail in the above annual report.)

## CONCLUSIONS:

Attainment of “optimal” primary care is strongly associated with adherence to breast, cervical and colorectal cancer screening for low income and minority women. The specific features of primary care most strongly associated with adherence to all types of recommended cancer screening for these women were: 1) Continuity with a usual source of care and with a specific clinician at that site which one sees for more (rather than fewer) of her visits, 2) Comprehensiveness of non-cancer screening services: e.g. practices which emphasized the comprehensive aspect of primary care with respect to counseling patients around health behaviors (non-cancer behaviors were measured). For mammogram and fecal occult blood testing, an additional feature of primary care which was associated with screening adherence was the coordination of care.

Women whose ambulatory systems reflected features of “optimal” primary care were more likely to receive all types of cancer screening and to be adherent to screening over time, regardless of their insurance status or socioeconomic status. While insurance status alone is a very important predictor of receipt of screening when assessed in models that do not fully account for the various components of primary care, it no longer predicts receipt of screening when one includes in the models the specific features of primary care. These findings argue that it is not insurance or financial access alone that facilitate screening utilization; but that when insurance facilitates entry into more “optimal” primary care systems women are more likely to adhere to screening recommendations. These findings carry special importance for policy implications for efforts to increase higher risk minority women's use of needed health care services. Providing women with insurance alone, while an important first step, will not guarantee use of recommended services unless it also facilitates their entry into ambulatory systems that provide optimal primary care.

**Strengths and Limitations:** Limitations of the proposed project include the generalizability to persons without telephones and the lack of validation of self-report data. With regard to use of the telephone, it is estimated that 94% of African-American households and 93% of Hispanic households in the District of Columbia have phones. (1990 U.S. Census for D.C., STF1) Use of population-based personal interviews would not be feasible given the resources available for the project. It is possible that those least likely to have access to primary care and to cancer screening will also be those persons without telephones, thus barriers perceived by this particular subgroup may be understated. With regard to validation of reports on screening, self-report generally overestimates the prevalence of screening.<sup>92-94</sup> Since this study involves a population-based sample, women will likely receive care from a variety of settings in Washington, D.C. Thus, validation of self-reports through medical record review will not be practical. Characteristics which might influence the validity of self-reports, such as education, socioeconomic status and acculturation will be controlled for in analyses.

Strengths include: 1) the population-based sampling which will provide information from those with little or no access to primary care, 2) the focus on an understudied group i.e. low-income minority women, 3) a sampling plan which reflects the demographic distribution of lower income women from throughout the District of Columbia, 4) prior work with focus groups to inform the development of the survey, 5) use of trained bilingual interviewers with CATI capability, 6) unique focus on the nature of features of primary care important to regular cancer screening from the perspective of women served, and 7) the mentoring and collaboration of experienced cancer control, primary care and behavioral researchers.

Implications: Assessment of the relationship between mutable features of primary care which promote early and ongoing use of recommended cancer screening in low-income women of color will help to target early breast cancer intervention efforts toward this traditionally under-served population. These findings are helping to develop a better understanding of the aspects of primary care which are most important to low-income women, and the role which attainment of those particular features plays in obtaining regular cancer screening. Findings will guide design of a future intervention that emphasizes important features of primary care in order to increase adherence to screening.

## APPENDICES

**Please Note: The 1<sup>st</sup> attached document: “Low-Income women whose ambulatory systems contain the features of optimal primary care are more likely to adhere to cancer screening recommendations.” (O'Malley et al.) summarizes the initial findings from the population-based telephone survey referred to in the body of this annual report and in the key research accomplishments for year 3.**

**Lower-income women whose ambulatory care systems contain the features of optimal primary care are more likely to adhere to cancer screening recommendations.**

**Short title: Primary care and cancer screening**

ABSTRACT

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## ABSTRACT

**Purpose:** To examine specific features of the structure and process of primary care that promote adherence to breast, cervical and colorectal cancer screening for low-income, predominantly African-American, urban women.

**Methods:** A bilingual computer assisted telephone interview of a population-based sample of 1205 low-income, predominantly African-American women age > 40 years in Washington, D.C. conducted Jan-March, 2000. Survey development was informed by focus groups from the same population. Integral features of primary care: continuity (visit-based), length of relationship with a usual source of care, accessibility (organizational, financial and geographic), comprehensiveness of services, and coordination of specialty care as well as aspects of the physician-patient relationship were all assessed with respect to the adherence to cancer screening.

**Results:** The survey response rate was 86%. In unadjusted analyses, visit-continuity with the same clinician, and a longer relationship with the usual source of care (longitudinality) were both significantly associated with adherence to all screening tests. Women attending settings with more comprehensiveness of services (counseling and of non-cancer screening services) were significantly more likely to adhere to screening than those whose ambulatory care sites lacked comprehensiveness. Patients who felt they had strong relationships with their physicians, or who felt that their physicians were compassionate, trustworthy and good communicators, were also significantly more likely to be adherent to screening. However, in final multivariate models only two primary care variables, continuity of care (visit-continuity), and comprehensiveness of services (counseling) were consistently associated with adherence to screening for all cancers. In adjusted analyses, continuity with a usual source of care\* and with a usual doctor that one sees at that place\* was strongly associated with adherence to clinical breast exams (OR 4.9\* & 8.0\*  $p \leq .01$ ), mammograms (OR 6.4\* & 6.4\*  $p \leq .01$ ), and pap smears (OR 2.8\* (NS) & 3.9\*,  $p \leq .01$ ) with a trend toward higher colorectal cancer screening (OR 5.8\* & 4.4\*). Going from uninsured, to public-insured only, to private (may also have public) insurance groups, there was a linear increase in the amount of continuity with a specific clinician at the usual source of care. (mean scores on the continuity index were 2.85 (SD .95), 3.25 (SD 0.85) and 3.42 (SD 0.73) respectively:  $F = 27.24$ ,  $p = .0001$ .) While insurance was a significant predictor of receipt of adherent screening for all tests in the unadjusted analyses, once the primary care variables were entered into the models, insurance was no longer significant.

**Conclusions:** Attainment of "optimal" primary care is strongly associated with adherence to breast, cervical and colorectal cancer screening for urban low income women of color. These findings suggest that insurance is important in assuring adherence to cancer screening services, to the extent that it facilitates the establishment of a continuous relationship with a clinician at a usual source of care which emphasized the features of optimal primary care. Findings will guide a future intervention that emphasizes important features of primary care in order to increase adherence to screening.

**Key words:** breast neoplasm, cervical neoplasm, colorectal neoplasm/ prevention and control\*, primary health care, continuity of patient care, insurance, women, ethnicity.



## INTRODUCTION

**Overview:** We assessed specific components of primary care and whether they were associated with adherence to breast, cervical and colorectal cancer screening over time among low-income women. We hypothesized that low-income women with greater attainment of the features of primary care will be more likely to receive ongoing cancer screening.

**Cancer screening in lower income minority women:** Regular use of mammography and clinical breast examination has been demonstrated to reduce breast cancer mortality by up to 30% among women aged 50 years or older.<sup>1-7</sup> Use of the pap test to screen for cervical cancer greatly reduces mortality from invasive cervical cancer by more than 70%.<sup>8</sup> Annual fecal occult blood testing and flexible sigmoidoscopy reduce colorectal cancer mortality by 31-57%.<sup>7</sup>

Yet, lower-income women in the District of Columbia, predominantly women of color, face marked racial and ethnic differences in breast, cervical and colorectal cancer morbidity and mortality.<sup>9-17</sup> For instance, relative survival rates for blacks are lower than for whites for all of these cancers; for breast cancer this excess mortality exists even though blacks have a lower incidence of breast cancer than whites.<sup>18-19</sup> Even after adjustment for socioeconomic status and for duration of symptoms, being black or Hispanic remains a risk factor for late stage diagnosis of breast, cervical and colorectal cancer.<sup>9-10, 18-19, 20-29</sup>

A large portion of the stage differential by race/ethnicity is related to different levels of exposure to cancer screening.<sup>27-31</sup> While national statistics show that black and Hispanic women are now receiving screening at rates comparable to Anglos, these are primarily rates of "ever" and "recent" screening.<sup>32-34</sup> Little data are available on adherence to (ongoing) screening for women in general<sup>35</sup> and even less is available on ongoing screening for minority women in community-based primary care settings. In addition, little research has been undertaken to identify barriers to participation in colorectal cancer screening.<sup>35</sup>

Progress has been made in narrowing the gap in screening rates between the minority and majority populations through the expansion of insurance coverage and through free cervical and breast cancer screening. (Cite CDC BCCEDP) However, universal free insurance alone does not appear to be enough to counteract the failure to target screening to the least-healthy and most vulnerable groups. (Roos LL et al, Med Care, 1999; other refs ?)

### Primary Care:

Having a regular source of care<sup>36-39</sup> and/or a physician recommendation for screening<sup>40-42</sup> are two of the most consistent predictors of cancer screening among minority and non-minority women. This relationship between the presence of a source of care and receipt of screening is especially important for uninsured women.<sup>39</sup> At present however, there is relatively little information available on the specific features of those sources of ambulatory care that are related to screening use, particularly for low-income women.<sup>43a-43d, 44</sup> There is also less information present for this high-risk population on how specific features of primary care interact with insurance in the access to and delivery of screening over time.

"Primary care" has been defined by the Institute of Medicine (IOM) as "the provision of integrated, accessible health care services by clinicians that are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community."<sup>45</sup> The key features of primary care include comprehensiveness, coordination, continuity, accessibility and accountability.<sup>46</sup>

Valid and reliable instruments exist to measure the features of primary care.<sup>45-52</sup> However, most of these have not been extended to low-income settings to identify aspects of primary care which are most relevant to low-income women from medically under-served areas.<sup>43a, 53</sup> Bindman et.al. found that "optimal primary care" was associated with recent use of cervical and breast cancer screening in a predominantly white privately insured sample in California.<sup>51</sup> Little has been done to assess the role of primary care in receipt of regular cancer screening in that population which is least likely to be screened, i.e. lower income black women. In addition, little work has been done to identify specific aspects of primary care that predict screening use.

There may be modifiable features of primary care systems, in addition to continuity of care, which lead to improved use of cancer screening for minority women. For instance, in a study of characteristics of primary care office systems as predictors of mammography utilization in older non-minority women where cost was not a barrier, specific office characteristics such as the process of scheduling mammograms, the use of flow sheets to prompt physicians (issues of organizational accessibility and of coordination of services) and patient reminders were associated with higher rates of recent screening.<sup>44</sup> One multi-component intervention in a community health center serving predominantly Hispanic and low-income persons, involved client education, staff training and management systems intervention strategies.<sup>55</sup> In studies of older black women, the structure of the delivery system (i.e. location of screening and long waiting periods for an appointment, e.g. issues of organizational accessibility), rather than cost, attributed to low cancer screening participation.<sup>56-59</sup> Difficulty in getting to a screening center is also a barrier to mammography screening.<sup>57-58</sup> One program for socio-economically disadvantaged women provides education and recruitment, low cost mammography, a one-stop screening site, and multidisciplinary evaluation and treatment.<sup>60</sup> Studies such as these have begun to assess some of the features of ambulatory systems associated with ever- and recent- use of cancer screening. We assessed specific components of primary care and whether they were associated with not only "ever" and "recent" use, but also of "adherence" over time to breast, cervical and colorectal cancer screening among low-income women. We hypothesized that low-income women with greater attainment of the features of primary care will be more likely to receive ongoing cancer screening.

## METHODS

**Focus Groups and Telephone Survey:** Telephone survey development was informed by a series of focus groups with lower income women aged over 40 in Washington, D.C. from four different primary care clinics. The methodology and findings from these focus groups have been summarized elsewhere. (JFP, 2000) For the current study, bilingual interviewers (Spanish/English) conducted a computer-assisted (CATI) population-based telephone survey.

Inclusion criteria included being female, age over 40 years, residing in Washington, D.C and living in a census tract of the District where at least 30% of the households had an income  $\leq$  200% of poverty threshold ( $\leq$  \$34,000.)

**Sampling Strategy:** The sample consisted of 25% random-digit-dial and 75% listed households merged with demographic information which targeted inclusion criteria. The distribution of household phone numbers reflected the population distributions in each of the lower income census tracts.

#### **Analysis Plan:**

**Dependent Variables:** In the process of examining features of primary care that promote screening, we focused our outcome measures on regular screening with **pap smears, clinical breast exams, and mammograms, and fecal occult blood testing**. There were multiple survey questions to ascertain the frequency of, and intervals between, screening throughout the women's age-eligible period for screening. **Adherence** (Last two routine screening tests were within the recommended intervals for age)<sup>69</sup> was measured, along with measuring "ever" and "recent" –use of each of the screening tests, all by self-report. However, since it is ongoing screening over time that correlates with mortality reduction, and since relationships between the primary care variables of interest and screening were consistent across utilization measures (ever, recent and adherent), we chose for simplicity to focus this paper on the more meaningful measure of "adherence."

**The Primary Independent Variables of Interest** were the health system variables (insurance status, features of primary care: accessibility, comprehensiveness of services, coordination of specialty care by the usual source of care, continuity and longitudinality), and the patient-clinician relationship. Other independent variables measured included personal characteristics: income, age, race/ethnicity, education, work status, marital status, acculturation, family size, whether one owns/rents home, health status-self assessed, cancer knowledge/attitudes and beliefs (cite Lannin JAMA) and knowledge of free screening services (cite Barbara Baldwin). With respect to cancer attitudes, knowledge and beliefs, seven items which were most strongly associated with receipt of screening for African-American women (Lannin) in prior studies were included in the survey.

**Power:** Since mammography had a low projected rate of regular use over time and since all women in the sample were age-eligible for mammographic screening (as opposed to FOBT which only women 50 years and over were eligible) we based our sample size calculations on the use of this test. For analyses in which a dichotomous outcome variable is used (regular versus non-regular screening) this sample size will provide power of 80% at the .05 (one-sided test) significance level to detect differences of 5% or greater between screening groups (e.g., regularly and non-regularly screened women) assuming a baseline of 25% regularly screened for the most conservative screening rates.<sup>27-28</sup> While this sample size was adequate to detect differences in receipt of pap smears, clinical breast exams and mammograms, we may have been underpowered to

assess relationships between the independent variables of interest and FOBT which has a lower projected rate of adherence.

**Analyses:** Univariate, bivariate and stratified analyses using  $\chi^2$  tests and t-tests as appropriate, were done prior to multivariate modeling. To analyze our measures of screening adherence we created a dichotomous outcome variable (adherent vs. non-adherent) to be analyzed in a multivariate logistic regression framework. Extensive exploratory analyses assessed unadjusted rates of screening and assessed for confounding. We also assessed for interaction between insurance, income, health status, and each of the primary care variables separately with respect to receipt of each of the screening tests. No interaction was found between any of these variables except for a small interaction effect between insurance and continuity of care. Models were done with and without the interaction terms for insurance and continuity, the change in odds ratios (ORs) was minimal. Final models were based on variables which had an association ( $p=.20$ ) with screening in stepwise (forward and backward elimination models), or which were significantly associated with screening in univariate analyses, or which we know from the literature have been shown to have an association with screening for this population. Since women over age 65 are likely to have Medicare, it is expected that we will see an age effect on screening which may be due to Medicare coverage of screening tests. Since comprehensiveness of non-cancer screening services was so likely to overlap conceptually with the comprehensiveness of cancer screening services, this construct of comprehensiveness (of non-cancer screening services) was not included in the multivariate models. Also, since such a large proportion of the sample had long-term relationships with their usual sources of care, likely due to the large Medicare proportion of the sample, this variable was not included in the final multivariate models. (Prior to excluding this "longitudinality" variable from the final models, its contribution to models was assessed and it had a minimal impact on the various odds ratios.) There is also, conceptual overlap between this longitudinality variable and the visit-continuity variable.

## RESULTS

The survey response rate was 86%. The survey took on average 25 minutes to complete. Table 1 describes the sample. The mean age was 64.8 years with a range from 41-96 years. Sixty percent of respondents had less than a high-school degree, or stopped their formal education upon completion of high-school or a GED. Individuals in the "don't know/refused" group for income behaved like the lowest income group in that they were least likely to have insurance, had the lowest educational status and were least likely to use screening and other health care services. This finding that the refusal group behaved like the lowest income respondents has been found in other studies as well. (Merzel, AJPH, 2000, June) The overwhelming majority of respondents were African-American and the percentages obtained in each racial/ethnic group reflect the population distribution of older women in the lower income areas begin targeted in the District of Columbia, based on the most recent census data. (ref) The majority of respondents had some form of health insurance, the bulk of this being due to Medicare. Self-reported health status was fair to poor for a large proportion of respondents (37.4%). Eight-four percent of respondents had a regular personal doctor or nurse.

Figures 1-4: Bar graphs display the unadjusted relationships between aspects of primary care and adherence to screening. There is a striking increase in adherence to screening for each increase in the amount of each primary care feature present.

Table 2 presents the unadjusted percentages of women screened according to the presence of specific features of primary care. Again, there are impressive correlations between greater presence of primary care features and the proportions of women adherent to recommendations for each screening test.

Table 3 presents the first phase of the regression models, e.g. "bivariate" regressions in which adherence to screening was regressed on a single feature of primary care, adjusting for all other socioeconomic and demographic variables. These bivariate regressions were done to assess the role of each individual primary care variable with respect to screening adherence while considering insurance primarily and adjusted for sex. The bivariate model where continuity is the main independent variable shows that insurance status is not a significant predictor of screening adherence once one considers whether continuity of care is present and to what degree. For each of the other models, where the main independent variable is each of the other primary care features, insurance still predicts screening adherence over 50% of the time. Note that for the fecal occult blood test adherence models since fewer respondents were eligible for FOBT, the numbers of women in each category of the four-level continuity variable are limited, this may account for the lack of significance in the continuity variable for this model and for the significance of the insurance variable in this model, when it was not significant in any of the other screening test-continuity models.

None of the knowledge/attitude/belief items were consistently associated with adherence to screening across all cancer screening tests. In unadjusted analyses (data not shown), for adherence to pap smears only two items correlated with screening: (thinking that cancer was God's punishment; and thinking that surgery causes cancer to grow faster,  $p \leq .01$  for each); 2 items were correlated with receipt of CBE: (Avoiding going to the doctor even when sick; and belief that if a person prays about cancer, God will heal it without medical treatments  $p \leq .01$  for each), and with mammogram adherence (Avoiding going to the doctor when sick  $p \leq .01$ ). When each of these items was included in the full multivariate models (table 4 bottom) predicting adherence to screening for the respective screening tests, the following remained significant correlates of adherence to screening: for pap smear (not thinking that surgery causes cancer to grow faster was correlated with adherence OR 1.6  $p = .006$ ), and for CBE and mammograms respectively (Not avoiding going to the doctor even when sick was correlated with adherence OR 1.5  $p = .02$ ; and OR 1.63  $p = .008$ ).

Table 4 presents the both the unadjusted and the adjusted (full) multivariate models. When models predicting the adherence to each of the cancer screening tests are constructed, insurance status is no longer a significant predictor after entry of the primary care variables into the model. The model also adjusts for income, education, home ownership, marital status, age, ethnicity and the interaction terms between insurance and continuity of care variables. These interaction terms

are also not significant in the final model, but in stratified analyses there was significant effect modification. Of all primary care variables, the continuity of care (with a place, a clinician at that place, and consistency of the clinician that one sees for most visits) variable is consistently an important predictor of receipt of each screening test. There is increasing likelihood of receipt of screening with each higher level of continuity for CBE (unadjusted and adjusted OR), for mammogram (unadjusted OR) and for all screening tests, there is a significant increase in the likelihood of receipt of adherent screening as one goes from: 1.) lacking a usual source of care to having a usual source of care, and 2.) just having a usual source of care, to having a usual source of care and a regular clinician at that site.

In unadjusted analyses, visit-continuity with the same clinician, and a longer relationship with the usual source of care (longitudinality) were both significantly associated with adherence to all screening tests. Women attending settings with more comprehensiveness of counseling services and of non-cancer screening were significantly more likely to adhere to screening than those whose ambulatory care sites lacked comprehensiveness. Patients who felt they had strong relationships with their physicians, or who felt that their physicians were compassionate, trustworthy and good communicators, were also significantly more likely to be adherent to screening. However, in final multivariate models only two primary care variables, continuity of care (visit-continuity), and comprehensiveness of services (counseling) were consistently associated with adherence to screening for all cancers. In adjusted analyses, continuity with a usual source of care\* and with a usual doctor that one sees at that place\* was strongly associated with adherence to clinical breast exams (OR 4.8\* & 8.0\*  $p \leq .01$ ), mammograms (OR 6.4\* & 6.4\*  $p \leq .01$ ), and pap smear (OR 2.8\* (NS) & 3.9\*,  $p \leq .01$ ) with a trend toward higher colorectal cancer (OR 5.8\* & 4.4\*) screening. Going from uninsured, to public-insured only, to private (may also have public) insurance groups, there was a linear increase in the amount of continuity with a specific clinician at the usual source of care. (mean scores on the continuity index were 2.85 (SD .95), 3.25 (SD 0.85) and 3.42 (SD 0.73) respectively:  $F = 27.24$ ,  $p = .0001$ .) While insurance was a significant predictor of receipt of adherent screening for all tests in the unadjusted analyses, once the primary care variables were entered into the models, insurance was no longer significant.

Lack of statistical significance for the adjusted ORs for FOB are likely due to small cell sizes, since FOB applies only to women over age 50 and among those women, there are so few of the older without a usual source of care.

## COMMENTS

Attainment of "optimal" primary care is strongly associated with adherence to breast, cervical and colorectal cancer screening for low income and minority women. The specific features of primary care most strongly associated with adherence to all types of recommended cancer screening for these women were: 1) Continuity with a usual source of care and with a specific clinician at that site which one sees for more (rather than fewer) of her visits, 2)

Comprehensiveness of non-cancer screening services: e.g. practices which emphasized the comprehensive aspect of primary care with respect to counseling patients around health behaviors (non-cancer behaviors were measured). For mammogram and fecal occult blood testing, an additional feature of primary care which was associated with screening adherence was the coordination of care.

Women whose ambulatory systems reflected features of "optimal" primary care were more likely to receive all types of cancer screening and to be adherent to screening over time, regardless of their insurance status or socioeconomic status. While insurance status alone is a very important predictor of receipt of screening when assessed in models that do not fully account for the various components of primary care, it no longer predicts receipt of screening when one includes in the models the specific features of primary care. These findings argue that it is not insurance or financial access alone that facilitate screening utilization; but that when insurance facilitates entry into more "optimal" primary care systems women are more likely to adhere to screening recommendations. These findings carry special importance for policy implications for efforts to increase higher risk minority women's use of needed health care services. Providing women with insurance alone, while an important first step, will not guarantee use of recommended services unless it also facilitates their entry into ambulatory systems that provide optimal primary care.

Strengths and Limitations: Limitations of the proposed project include the generalizability to persons without telephones and the lack of validation of self-report data. With regard to use of the telephone, it is estimated that 94% of African-American households and 93% of Hispanic households in the District of Columbia have phones. (1990 U.S. Census for D.C., STF1) Use of population-based personal interviews would not be feasible given the resources available for the project. It is possible that those least likely to have access to primary care and to cancer screening will also be those persons without telephones, thus barriers perceived by this particular subgroup may be understated. With regard to validation of reports on screening, self-report generally overestimates the prevalence of screening.<sup>92-94</sup> Since this study involves a population-based sample, women will likely receive care from a variety of settings in Washington, D.C. Thus, validation of self-reports through medical record review will not be practical. Characteristics which might influence the validity of self-reports, such as education, socioeconomic status and acculturation will be controlled for in analyses.

Strengths include: 1) the population-based sampling which will provide information from those with little or no access to primary care, 2) the focus on an understudied group i.e. low-income minority women, 3) a sampling plan which reflects the demographic distribution of lower income women from throughout the District of Columbia, 4) prior work with focus groups to inform the

development of the survey, 5) use of trained bilingual interviewers with CATI capability, 6) unique focus on the nature of features of primary care important to regular cancer screening from the perspective of women served, and 7) the mentoring and collaboration of experienced cancer control, primary care and behavioral researchers.

Implications: Assessment of the relationship between mutable features of primary care which promote early and ongoing use of recommended cancer screening in low-income women of color will help to target early intervention efforts toward this traditionally under-served population. These findings are helping to develop a better understanding of the aspects of primary care which are most important to low-income women, and the role which attainment of those particular features plays in obtaining regular cancer screening.

**(I need to develop this section much more, but am awaiting your read of the data and review of this draft so that it ends up being consistent with the rest of the paper.)**



**Acknowledgement:**

The authors would like to thank the women who so generously gave of their time to respond to this telephone survey. Thanks as well goes to extremely dedicated clinicians and medical directors: Dr. Randi Abramson, Sister Kay Koppes and Dr. Cheryl Williams and Dr. Oxiris Barbot who allowed and facilitated our recruitment of focus group volunteers from their clinics during the first phase of the study.

**Table 1. Characteristics of the Sample (N=1205 Women)**

	%
<b>Age</b>	64.8 years
Mean (years)	41-96 years
Range	16.3%
Categories: 41-49 years	31.5
50-65	52.2
> 65	
<b>Education (Highest completed)</b>	
< 12 years	26.3
HS grad/GED	33.5
≥ Some college	40.2
<b>Income</b>	
DK/REF	26.9
<\$10K	11.5
\$10-20 K	15.9
\$20-30K	15.1
\$30-40 K	11.4
\$>40K	19.2
<b>Self-identified Ethnicity/Race</b>	
Black/African-American	82.7
Caucasian	6.6
Hispanic/ Other	3.7
Refused	7.0
<b>Owns Home (vs. Rents)</b>	66.2
<b>Work Status</b>	
Retired/Disabled	62.6
Working Full-time	24.3
Working Part-time	6.4
Unemployed/ Homemaker/ Student/ DK/REF	7.2
<b>Married/living as married</b>	26.5
<b>Family Size</b>	2.1 (mean)
≥4 persons/household	12.4
<b>Health Status (self-assessed)</b>	
Poor-Fair	37.4
Good	36.4
Very good-Excellent	26.2
<b>Has a regular personal doctor/nurse</b>	84.8
<b>Health Insurance coverage for any period during the past 12 months</b>	
Public Only	22.8
Private (may also have had Medicare/Medicaid)	67.9
Uninsured for the entire 12 months	9.3

Table 2. Unadjusted Percentages of Women Screened, According to Presence of Specific Features of Primary Care. N=1205 Lower Income Women, Washington, D.C. 2000.

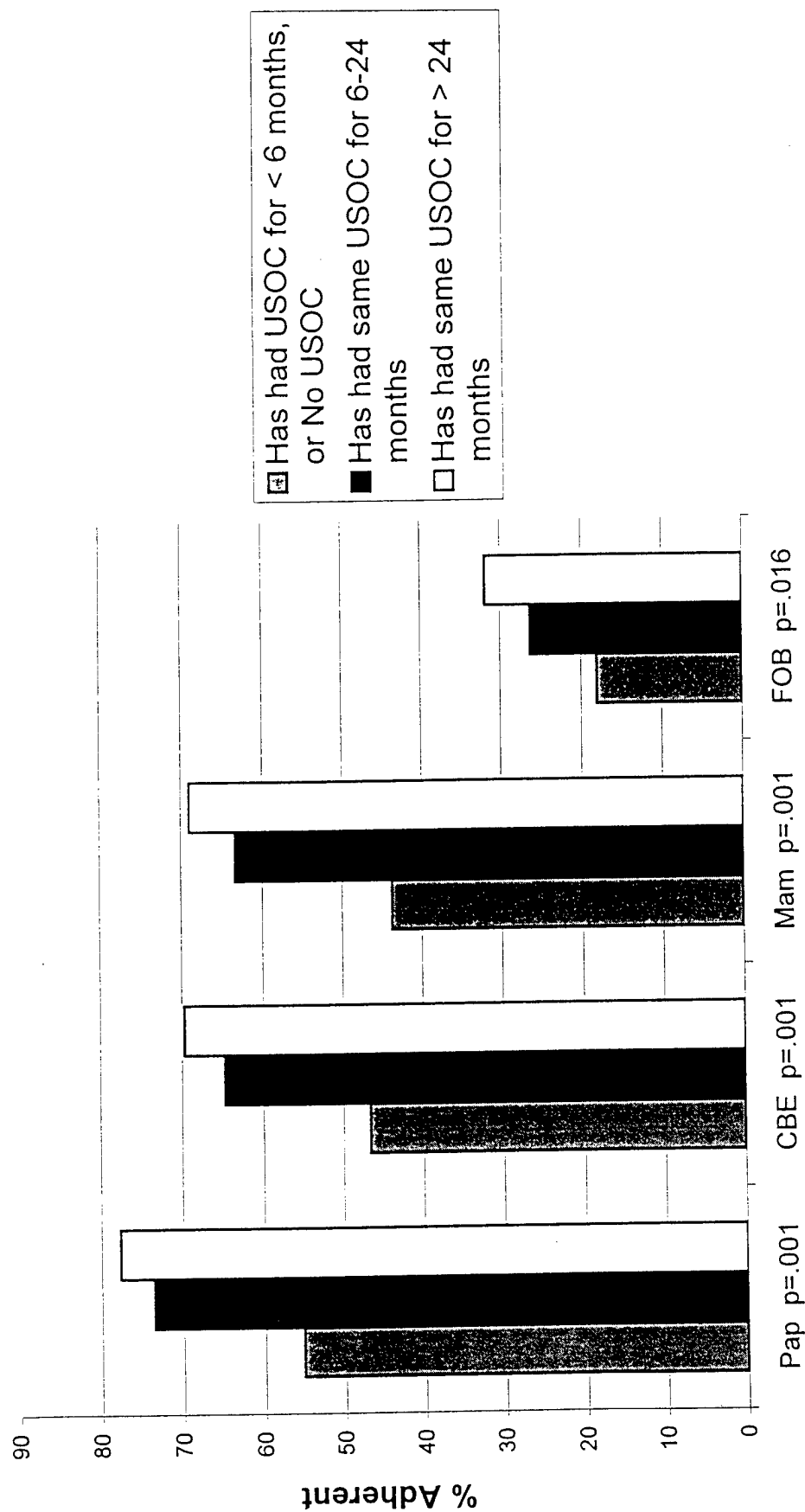
Screening Test- (Adherence)

Specific Feature of Primary Care	Pap	CBE	Mam	FOB
	%	%	%	%
<i>Continuity—Concentration</i>				
No Usual Source of Care (USOC)	41.2	23.5	29.4	11.5
USOC (has a place only)	68.5	60.4	53.0	24.3
USOC and Reg Doc, but Doesn't See at all visits	76.9	64.7	66.5	33.3
USOC and Reg Doc; Does See for all visits	76.7	71.5	69.7	28.9
	p=.001	p=.001	p=.001	p=.051
<i>Continuity—"Longitudinality"</i>				
Has had USOC for < 6 months (or no usoc)	55.2	46.7	43.8	18.1
Has had same USOC for 6-24 months	73.6	64.8	63.4	26.3
Has had same USOC for > 24 months	77.7	69.7	69.0	31.9
	p=.001	p=.001	p=.001	p=.016
<i>Access—Organizational</i>				
Low (lowest quartile)	71.2	63.5	64.6	29.1
Mid (mid-two quartiles)	78.2	67.1	63.5	31.7
High (top-quartile)	76.9	71.0	68.9	27.5
	p=.037	p=.073	p=.294	p=.549
<i>Access-Geographic</i>				
Low	69.5	64.9	61.1	22.2
Mid	74.6	63.7	62.4	29.6
High	76.9	69.2	69.4	31.0
	p=.188	p=.150	p=.028	p=.194
<i>Access-Financial</i>				
Low	70.8	63.3	62.7	29.1
Mid	80.3	71.9	66.6	28.9
High	78.7	66.7	67.9	33.3
	p=.005	p=.031	p=.408	p=.590

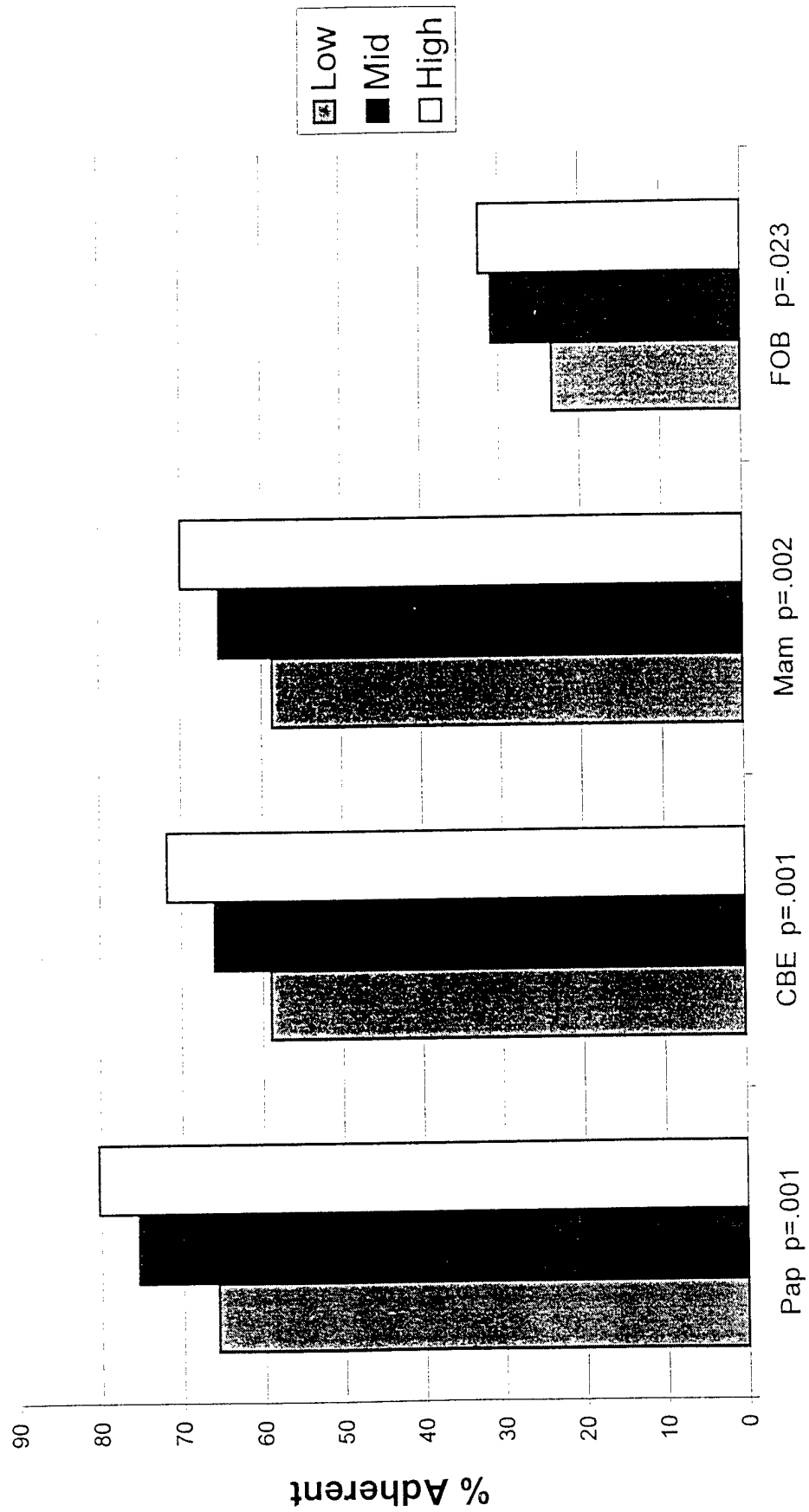
<b>Comprehensiveness—All needs met</b>				
Low	68.5	66.2	59.2	22.1
Mid	73.7	62.9	63.6	26.9
High	78.3	71.0	69.4	32.8
	p=.037	p=.022	p=.033	p=.045
<b>Comprehensiveness—(of Non-cancer Screening)</b>				
Low	29.8	19.2	17.0	3.0
Mid	64.3	47.5	57.4	17.1
High	78.8	72.0	69.4	32.2
	p=.001	p=.001	p=.001	p=.001
<b>Comprehensiveness—Counseling</b>				
Low	65.6	58.5	60.4	25.3
Mid	79.7	70.8	70.6	30.5
High	77.4	69.4	61.7	34.2
	p=.001	p=.001	p=.002	p=.089
<b>Patient Physician Relationship—Compassion</b>				
Low (lowest quartile)	65.8	59.0	58.7	23.4
Mid (mid two quartiles)	75.5	66.0	65.3	31.0
High (top quartile)	80.3	71.8	70.0	32.5
	p=.001	p=.001	p=.002	p=.023
<b>Patient Physician Relationship—Trust</b>				
Low	61.3	51.4	58.6	21.0
Mid	78.6	67.6	66.7	27.3
High	75.9	68.3	66.5	30.9
	p=.002	p=.002	p=.243	p=.161
<b>Patient Physician Relationship—Communication</b>				
Low	66.9	57.5	58.5	26.6
Mid	71.5	64.1	64.1	28.5
High	79.2	70.2	68.4	31.1
	p=.002	p=.012	p=.086	p=.571
<b>Coordination – of Specialist Care (N=748)</b>				
Low (lowest quartile)	75.9	63.2	63.2	20.0
Mid (mid two quartiles)	79.7	69.2	71.7	32.7
High (top quartile)	80.9	77.9	70.4	37.4
	p=.508	p=.005	p=.177	p=.010

Adherence is defined for each screening test as having obtained the last two tests within age appropriate intervals based on NCI and ACS guidelines: Ex. Mammogram adherence = last mammogram was for a routine screening exam, was within the past two years, and also had a mammogram during the immediate two years before that “recent” one.  
CBE = Clinical Breast Exam Mam = Mammogram Pap = Pap Smear FOBT= Fecal Occult Blood Test

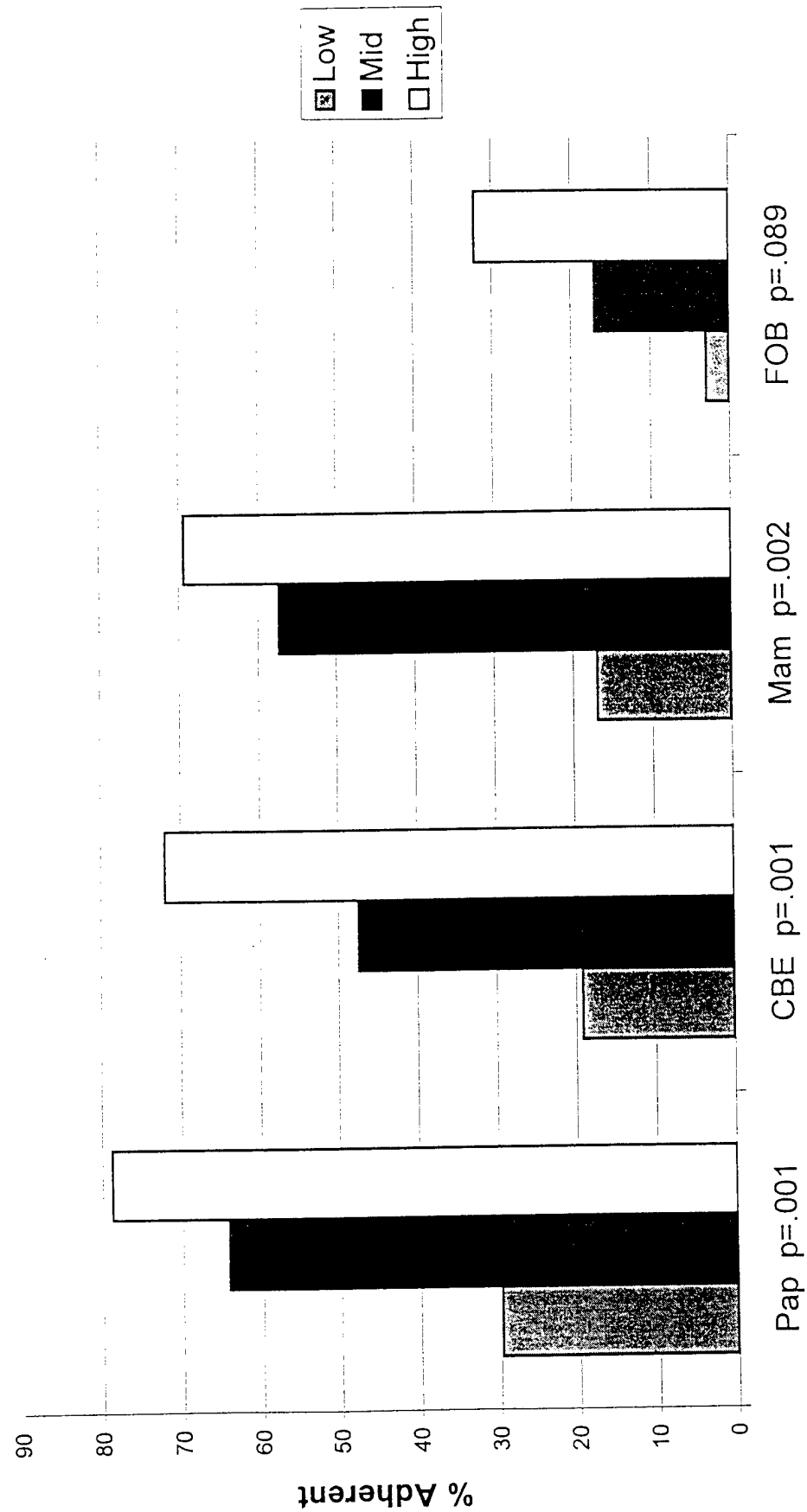
# Adherence to Screening by the Length of Relationship With the Usual Source of Primary Care



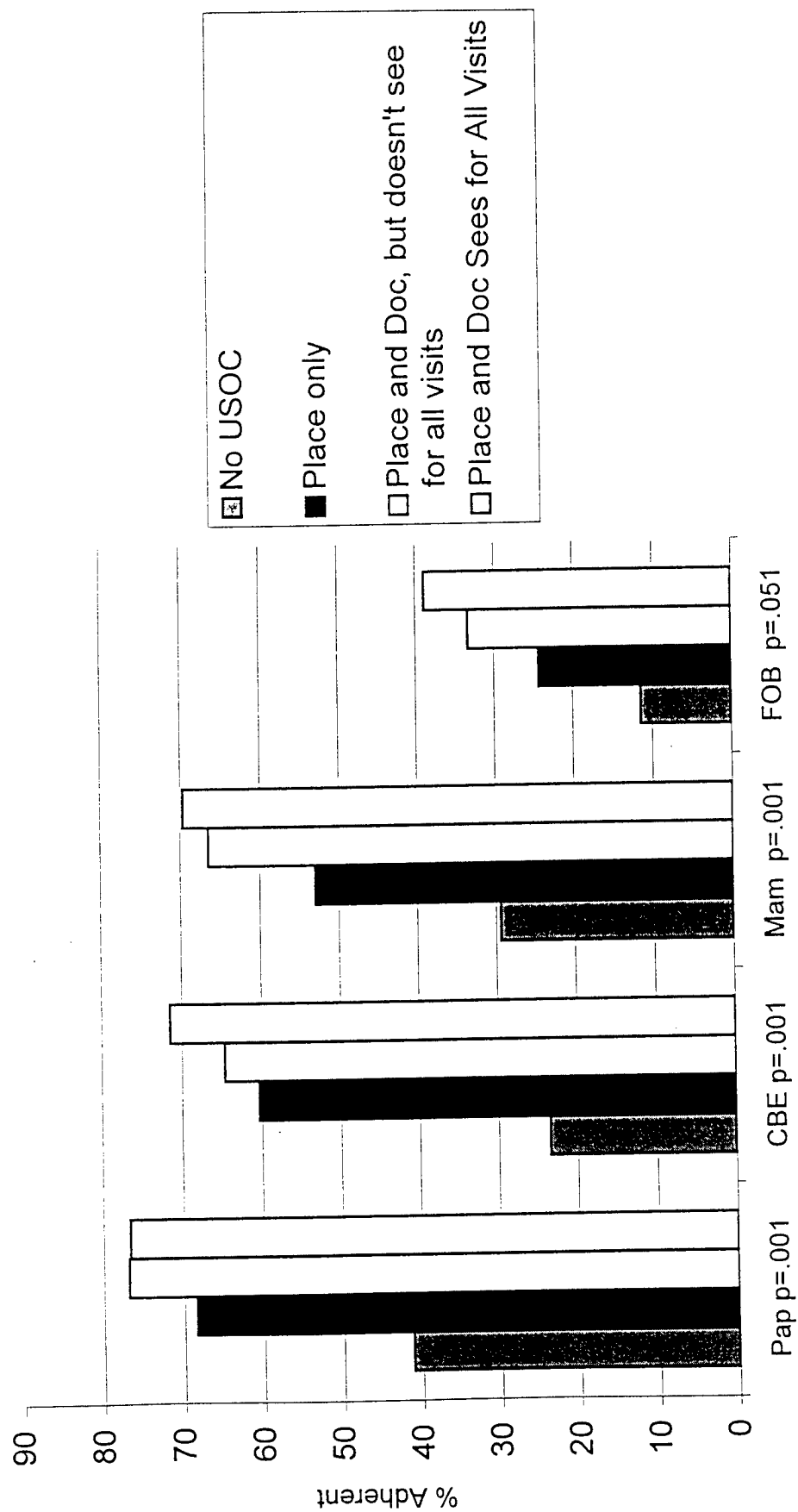
## Adherence to Screening by the Strength of the Patient-Physician Relationship



# Adherence to Screening by the Degree of Comprehensiveness Present



# Adherence to Screening by Degree of Continuity with the Usual Source of Care





# ANOVA for continuity and insurance

F value 27.24      p=0.0001

Mean score on Continuity Index (SD)	
No insurance	2.85 (0.96)
Public insurance only	3.27 (0.85)
Private insurance (may also have public)	3.42 (0.73)

## Insurance Status of the sample Stratified by Age:

<u>&lt; 65 years</u>	Freq	%
Uninsured	70	13.2%
Public only	100	18.8%
Private (may also have public)	362	68%

<u>≥65 years</u>	Freq	%
Uninsured	41	6.3%
Only Medicare	355	54.7%
Dual eligibles	34	5.2%
Private	219	33.7%

**Table 3. (Just to understand relationships, too much to include in a publication)**  
**Bivariate regressions of each primary care (independent) variable separately with the screening adherence variables as outcomes, and adjusted for all SES variables: (age, education, race/ethnicity, home ownership, income, marital status, health status, insurance status).**

**Screening Adherence (OR)**

Models 1

	Pap	CBE	Mam	FOB
<i>Continuity—Concentration</i>				
No Usual Source of Care (USOC)	1	1	1	1
USOC (has a place only)	2.9**	4.7**	2.7*	2.3
USOC and Reg Doc, but Doesn't See at all visits	4.6**	5.6**	4.1**	3.1
USOC and Reg Doc; Does See for all visits	4.3**	7.4**	4.4**	2.4
<b>Insurance (ref group is the uninsured)</b> (NS=not significant)	Ins NS	Ins NS	Ins NS	Pub 2.2* Priv 2.4**

Models 2

	Pap	CBE	Mam	FOB
<i>Access—Organizational</i>				
Low (lowest quartile)	1	1	1	1
Mid (mid-two quartiles)	1.3	1	0.7	1.0
High (top-quartile)	1.2	1.2	0.8	0.7
<i>Access-Geographic</i>				
Low	1	1	1	1
Mid	1.5*	0.9	1.1	1.3
High	1.4	1.0	1.6*	1.5
<i>Access-Financial</i>				
Low	1	1	1	1
Mid	1.4*	1.4**	1.0	0.9
High	1.1	1.2	1.1	1.2
<b>Insurance (ref group is the uninsured)</b>	Priv 1.6* Pub NS	Ins NS	Priv 1.6* Pub NS	Priv 2.5** Pub 2.2*

Models 3

	Pap	CBE	Mam	FOB
<i>Comprehensiveness—All needs met</i>				
Low	1	1	1	1
Mid	1.5*	1	1.2	1.1
High	1.8**	1.4	1.5*	1.4
<i>Comprehensiveness—Counseling</i>				
Low	1	1	1	1
Mid	2.0**	1.7**	1.6**	1.3
High	1.8**	1.7**	1.3	1.6**
<b>Insurance (ref group is the uninsured)</b>	Ins NS	Ins NS	Priv 1.5* Pub NS	Priv 2.4** Pub 2.1*

Models 4

	Pap	CBE	Mam	FOB
<b><i>Patient Physician Relationship—Compassion</i></b>				
Low (lowest quartile)	1	1	1	1
Mid (mid two quartiles)	1.5*	1.2	1.3	1.4
High (top quartile)	1.6*	1.3	1.5*	1.4
<b><i>Patient Physician Relationship—Trust</i></b>				
Low	1	1	1	1
Mid	2.0**	1.6	1.1	1.2
High	1.7*	1.7*	1.0	1.3
<b><i>Patient Physician Relationship—Communication</i></b>				
Low	1	1	1	1
Mid	1	1	1	1
High	1	1	1	1
<b>Insurance (ref group is the uninsured)</b>	Priv 1.6* Pub NS	Ins NS	Priv 1.6* Pub NS	Priv 2.4** Pub 2.2*

Model 5

	Pap	CBE	Mam	FOB
<b><i>Coordination – of Specialist Care (N=748)</i></b>				
Low (lowest quartile)	1	1	1	1
Mid (mid two quartiles)	1.6*	1.4*	1.4**	1.5*
High (top quartile)	1.5*	2.0**	1.3	1.8**
<b>Insurance (ref group is the uninsured)</b>	Priv 1.6* Pub NS	Ins NS	Priv 1.6* Pub NS	Priv 2.3** Pub 2.1*

Table 4. Odds of Adhering to Screening, According to Presence of Specific Features of Primary Care. N=1205 Lower Inc Women, Washington, D.C. 2000. OR=Crude odds ratio; ORa=Adjusted† odds ratio \*p≤.05 \*\*p≤.01

Specific Feature of Primary Care	Screening Test- (Adherence)							
	Pap		CBE		Mam		FOB	
	OR	ORa	OR	ORa	OR	ORa	OR	ORa
<i>Continuity—Concentration</i>								
No Usual Source of Care (USOC)	1	1	1	1	1	1	1	1
USOC (has a place only)	3.1**	2.8	5.0**	4.9**	2.7*	6.4**	2.5	5.8
USOC and Reg Doc. but Doesn't See at all visits	4.7**	3.9**	6.0**	4.5**	4.8**	4.7**	3.8*	4.4
USOC and Reg Doc; Does See for all visits	4.7**	3.8**	8.1**	8.0**	5.5**	6.4**	3.1*	2.6
<i>Continuity—"Longitudinality"</i>	NOT IN MODEL SINCE MANY WOMEN HAD LONG RELATIONSHIPS with a Usual Source of Care							
<i>Access—Organizational</i>								
Low (lowest quartile)	1	1	1	1	1	1	1	1
Mid (mid-two quartiles)	1.5*	1.0	1.2	0.8	1	0.6**	1.1	0.8
High (top-quartile)	1.4*	0.9	1.4*	0.8	1.2	0.6*	1.0	0.6*
<i>Access-Geographic</i>								
Low	1	1	1	1	1	1	1	1
Mid	1.5*	1.3	1.0	0.8	1.1	1.0	1.5	1.3
High	1.7**	1.2	1.3	0.8	1.6*	1.5*	1.6	1.4
<i>Access-Financial</i>								
Low	1	1	1	1	1	1	1	1
Mid	1.8**	1.3	1.6**	1.4*	1.1	1.0	1.0	0.9
High	1.2	1.0	1.3	1.2	1.2	1.1	1.2	1.2
<i>Comprehensiveness—All needs met</i>								
Low	1	1	1	1	1	1	1	1
Mid	1.5*	1.1	1.1	0.7	1.3	1	1.2	1
High	1.9**	1.0	1.5*	0.8	1.7**	1.3	1.5*	1.3
<i>Comprehensiveness—Non cancer screening</i>								
Low	1	Not in model	1	Not in model	1	Not in model	1	Not in model
Mid	4.8**		4.6**		8.0**		7.9*	
High	9.9**		13.1**		13.3**		18.0**	
<i>Comprehensiveness—Counseling</i>								
Low	1	1	1	1	1	1	1	1
Mid	2.0**	1.8**	1.7*	1.5**	1.6*	1.6**	1.3	1.2
High	1.8**	1.6*	1.6**	1.6**	1.1	1.2	1.6*	1.5*

<b>Patient Physician Relationship—Compassion</b>								
Low (lowest quartile)	1	1	1	1	1	1	1	1
Mid (mid two quartiles)	1.6**	1.4	1.3	1.1	1.3	1.2	1.5*	1.3
High (top quartile)	2.1**	1.7*	1.8**	1.2	1.6**	1.4	1.6**	1.4
<b>Patient Physician Relationship—Trust</b>								
Low	1	1	1	1	1	1	1	1
Mid	2.4**	1.6	1.9**	1.5	1.5	1.0	1.5	1.2
High	2.1**	1.3	2.0**	1.4	1.5*	0.8	1.7*	1.3
<b>Patient Physician Relationship—Communication</b>								
Low	1	1	1	1	1	1	1	1
Mid	1.4	0.8	1.4	1.0	1.4	1.0	1.3	0.8
High	2.2**	0.9	1.8**	1.8	1.7**	0.9	1.5	0.7
<b>Coordination – of Specialist Care (N=748)</b>								
Low (lowest quartile)	1	1	1	1	1	1	1	1
Mid (mid two quartiles)	1.8**	1.4	1.5**	1.3	1.7**	1.3	1.6**	1.4
High (top quartile)	1.9**	1.2	2.4**	1.8**	1.6**	1.1	1.9**	1.7*
<b>Insurance</b>								
Uninsured	1	1	1	1	1	1	1	1
Public Only	0.9	1.6	0.9	1.3	1.0	0.9	2.1*	1.0
Private (May also have Public)	1.8**	2.5	1.4	1.5	2.2**	1.3	2.7**	1.3

†Adjusted for insurance, income, health status, age, ethnicity, marital status, education, and interaction between insurance and continuity of care. Adherence is defined for each screening test as having obtained the last two tests within age appropriate intervals based on NCI and ACS guidelines:  
 Ex. Mammogram adherence = last mammogram was for a routine screening exam, was within the past two years, and also had a mammogram during the immediate two years before that “recent” one

CBE = Clinical Breast Exam    Mam = Mammogram    Pap = Pap Smear    FOB = Fecal Occult Blood Test

NOTE: Insurance was not a significant covariate in any final model where all of the primary care variables are independent variables.

Other significant variables in the final models:	<u>Pap</u>	<u>CBE</u>	<u>Mam</u>	<u>FOB</u>
	income+	educ+	age+	health+
	Age+	own+	educ+	
	(due to	age due	own+	
	Medicare)	to Medicare	Income+	
	Belief that	Avoids dr.	Avoids dr.	
	surgery increases	if sick -	if sick -	
	risk -			

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## Low-Income Women's Priorities for Primary Care

### A Qualitative Study

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**BACKGROUND** ■ Because of their challenging social and economic environments, low-income women may find particular features of primary care uniquely important. For this qualitative study we explored which features are priorities to women from low-income settings and whether those priorities fit into an established primary care framework.

**METHODS** ■ We performed a qualitative analysis of 4 focus groups of women aged 40 to 65 years from 4 community health clinics in Washington, DC. Prompted by semistructured open-ended questions, the focus groups discussed their experiences with ambulatory care and the attributes of primary care that they found important. The focus groups were audiotaped, and the tapes were transcribed verbatim and coded independently by 3 readers.

**RESULTS** ■ The comments were independently organized into 5 content areas of primary care service delivery plus the construct of patient-provider relationship in the following order of frequency: accessibility (37.4%), the physician-patient relationship (37.4%), comprehensive scope of services (11.5%), coordination between providers (6.8%), continuity with a single clinician (3.7%), and accountability (3.2%). Commonly reported specific priorities included a sense of concern and respect from the clinicians and staff toward the patient, a physician who was willing to talk and spend time with them (attributes of the physician-patient relationship), weekend or evening hours, waiting times (attributes of organi-

zational accessibility), location in the inner city and on public transport routes (an attribute of geographic accessibility), availability of coordinated social and clinical services on-site; and, availability of mental health services on-site (attributes of comprehensiveness and of coordination).

**CONCLUSIONS** ■ All attributes of care that were priorities for low-income women fit into 1 of 6 content areas. Specific features within the content areas of accessibility, physician-patient relationship, and comprehensiveness were particularly important for these women.

**KEY WORDS** ■ Primary health care; poverty; health priorities; patient satisfaction; women. (*J Fam Pract* 2000; 49:141-146)

The literature examining specific attributes of the structure and process of primary care for lower-income populations that suffer from disproportionately poor health<sup>1</sup> is relatively modest.<sup>2</sup> Most research in primary care has been undertaken in predominantly insured middle-class private settings and in children.<sup>3-8</sup> There may be particular features of primary care that are uniquely important to low-income women given their challenging social and economic environments.

Ideally, primary care provides entry into the system for all new health needs, involves person-focused (not disease-oriented) care over time, includes care for all but very uncommon or unusual conditions, and coordinates services delivered by multiple providers.<sup>9</sup> In accepted conceptual frameworks of primary care, the essential features include: a comprehensive range of services, coordination across providers, continuity with a single provider, an accessible source of care, and accountability.<sup>9-10</sup>

The purposes of our qualitative study were to determine which particular attributes of primary care were priorities for low-income women and to investigate whether an accepted framework for the conceptualization of primary care<sup>9-10</sup> corresponds to the priorities of low-income women aged 40 years and

\*Definitions for these features can be found on the *Journal's* Web site, [www.jfampract.com](http://www.jfampract.com).

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**TABLE 1****Focus Group Questions**

When you think about the place where you go for health care, what kinds of things are most important to you?
What do you think about the care that you receive at (XYZ) clinic?
What are the good things about your care there?
What are the bad things about your care?
Is there anything about your care that could be improved?
What would keep you from coming to (XYZ) clinic if you needed care or had any type of questions about your health?
What would be the characteristics of the ideal clinic, that would make you want to go there for your care?
Where would this clinic be located?

NOTE: A short demographic questionnaire was circulated and read aloud with the women at the end of each focus group.

older. We hypothesized that themes raised by low-income women would fit into an established framework of primary care, but particular attributes of the features of primary care would be especially important to this vulnerable population.

## METHODS

### Study Design

We recruited focus group participants using posters and flyers circulated at 4 community clinics in Washington, DC. Those clinics were selected because of their location in medically underserved communities in 3 of the poorest wards of Washington, DC, and because they were examples of the range of structure and funding sources. We used in-depth interviews, audiotaped focus groups,<sup>11</sup> and content analysis of the verbatim transcripts<sup>12</sup> to identify attributes of primary care that are important to low-income women. At completion of the fourth focus group, similar themes continued to be raised, indicating saturation of themes. Through an iterative process of listening to audiotapes and reading transcripts, an exhaustive taxonomy was created that identified groups of issues that low-income women identified as important in the receipt of primary care.

### Focus-Group Participants

The participants were English- or Spanish-speaking women aged 40 years or older who used the clinic for their current care or who had used the clinic in the past and were able to give informed consent. Since our qualitative study is the first component of a larger study to assess the relationship between priorities for primary care and receipt of cancer screening services for low-income women, we restricted the sampling frame to women aged 40 years and older.

### Conduct of Focus Group Sessions

A separate focus group was held for each clinic. All focus groups were conducted in convenient, safe, and neutral community settings, and clinic staff was not present. The sessions lasted approximately 2

hours. A total of 24 women participated in the 4 focus groups: 2 of predominantly African American patients facilitated by an independent experienced African American female moderator and 2 of Spanish-speaking patients, conducted in Spanish by an experienced Latin American age-appropriate female moderator. A series of open-ended questions was asked of participants to elicit feelings about and experiences with primary care. (Table 1).

### Development of Taxonomy

Two study team members (an internist and a physician researcher) independently reviewed each transcript in its entirety, identifying distinct topics (themes) and making comments indicating each of these units of text. Repeated or reworded statements of the same idea by the same participant were listed together as one comment.

Each unit of text (a statement that conveyed one idea) from the transcripts was listed by a physician primary care researcher in the order it arose in the transcripts as both a direct quote and as a summary theme on the basis of the comments made by the first 2 study team members. Initially, to avoid imposing any particular framework onto the women's comments, 2 investigators did independent inductive coding,<sup>13-14</sup> in which each unit of text was reviewed in its context from the transcript, categories (labels) were generated, and a list of labels was compiled. When reviewing this exhaustive list, we found that the list of inductive labels (codes) fit fairly well into established conceptual frameworks for primary care. Thus, all units of text from the transcripts were then reclassified independently in duplicate (by a clinical internist and by a physician primary care researcher), using agreed-upon coding rules from the primary care conceptual framework, with the addition of the physician-patient relationship category, which arose as a common theme from the transcripts.

Interrater reliability for the overall coding of distinct units of text into 1 of 6 major primary care content areas was substantial ( $\beta = 0.84$  overall). Content

analysis was performed on the comments for all 4 focus groups, including a count of the number of times a theme was mentioned by different respondents and the primary care content area into which the themes fit.

## RESULTS

A total of 24 women participated in the discussions: 8 Latinas, 15 African Americans, and 1 white woman. The mean age of the participants was 46.6 years (median = 44.5; one third were aged 50 years and older.) Eight of the participants had an 11th grade education or less; 5 were high-school graduates; and 11 had some college education. Four were married. The majority worked: 8 full time, 8 part time, and the rest were unpaid, retired, or unemployed. Sixteen of these women cared for dependents part or full time. Eighty-two percent of the participants had a household income of less than

\$20,000, reflecting our success in recruiting the population we sought. Twenty-two women were uninsured, but most of the African American participants had had Medicaid or private insurance in the past.

The most important conceptual modification arising from the women's comments was the addition of the physician-patient relationship as an important and unique feature encompassing many of the women's priorities. The percentages of focus group participant comments falling into each of the major primary care codes were as follows: an accessible source of care (37.4%), the physician-patient relationship (37.4%), a comprehensive range of services (11.5%), coordination across providers (6.8%), continuity with a single provider (3.7%), and accountability (3.2%). Table 2 gives the frequency distribution of participants' priorities for primary care and some of the more commonly stated priorities.

Within the content area of the physician-patient

**TABLE 2**

### Sample of Low-Income Women's Priorities for Primary Care Identified in Focus Groups

#### Accessibility 37.4\*

- Available to those without insurance/low costs of services (12)†
- Attentiveness to waiting times to get an appointment and to be seen once at the clinic (12)
- Weekend or evening hours/convenient appointment times (10)
- Doctor and staff fluent in Spanish/test results mailed in Spanish (Hispanic participants) (9)
- Location in inner city or on public transport (9)

#### Physician-Patient Relationship 37.4

- Concerned, respectful staff (29)
- Doctor willing to talk and listen (10)
- Clinician from the same culture/knowledgable about the immigrant community (Hispanic participants) (7)

#### Comprehensiveness 11.5

- Multiple services available on-site: mental health, counseling, dental, preventive (8)
- Up-to-date facility and equipment (6)

#### Coordination 6.8

- Integration of social services (eg, social security, HUD, food stamps) (5)
- Ease of getting well-coordinated referrals to outside services and to a wide range of hospitals (5)

#### Continuity 3.7

- Providers that you know from the past (6)

#### Accountability 3.2

- Quality of care (3)
- Reputation in the community (2)
- Happy with care (satisfaction) (1)

HUD denotes US Department of Housing and Urban Development.

\*Percentage of total comments for which each content area accounted.

†Number of times each specific theme was mentioned by different individuals.

**TABLE 3**

**Sample Comments from the Focus Groups Organized  
by Primary Care Content Areas**

Category	Sample Comments
<b>Comprehensiveness<sup>9-10</sup></b>	<ul style="list-style-type: none"> <li>• "It's really surprising, all the things that are going on in that one clinic. In some ways it's better than a private doctor."</li> <li>• "They even have someone to talk to you about depression."</li> <li>• "I went in to get more blood pressure medicine, and instead of just giving me the medicine, the doctor said that I was supposed to have this done, breast exam, Pap smear, shots. The doctor took the time to give me all this stuff."</li> </ul>
<b>Coordination<sup>9-10</sup></b>	<ul style="list-style-type: none"> <li>• "They [clinic staff] kept calling me to reach me about my mammogram. It really made me feel good to know that there is someone there who really cares."</li> <li>• "I think the clinic should have a doctor and social worker to go through social security, because if you have a disability, you have to go through a whole lot of problems with your disability."</li> </ul>
<b>Continuity<sup>9-10</sup></b>	<ul style="list-style-type: none"> <li>• "I had a long treatment and then my Medicaid was cut. The relationship between the doctor and the patient is very important. I wanted to see the same doctor."</li> <li>• "I want a doctor who gets to know me."</li> </ul>
<b>Accessibility<sup>9-10</sup></b>	<ul style="list-style-type: none"> <li>• "The clinic needs to be right here, in my neighborhood, or near a bus or subway."</li> <li>• "I had chosen a private doctor myself, but I could never talk to her. I could never get in contact with her ... so, that's when I ended up coming back [to the clinic]."</li> <li>• "Communication gets lost with translation. It is not the same if you explain directly to the doctor what you feel, as to tell somebody else who will translate to the doctor in their own way."</li> </ul>
<b>Physician-Patient Relationship<sup>27</sup></b>	<ul style="list-style-type: none"> <li>• "The whole staff makes you feel like a human being and that you are important."</li> <li>• "I think they give really good care, because the first time I came here, they explained to me what was going on."</li> <li>• "I would like for the doctor to talk with me, to tell me what problems I have, and to have an interest in my concerns."</li> </ul>
<b>Accountability<sup>10</sup></b>	<ul style="list-style-type: none"> <li>• "You want a high level of health care at a totally professional level."</li> <li>• "If it has a good reputation, you go there, and if you still receive that type of treatment that everybody else says that they are getting there, then that makes you want to go back. Like at [Medicaid managed plan X], I've been there more times in the last couple of months, than I'd been with my other [private] doctor."</li> </ul>

relationship, themes mentioned most often were communication between physician and patient, having staff who listen, getting personal attention, and most important, a staff that was concerned and respectful. For Latinas, clinicians' knowledge of the

Latin community and of the fear and trust issues experienced by recent immigrants toward the medical system and toward other members of the community were mentioned often.

Specific attributes mentioned frequently within

the category of accessibility were a clinic that had evening and weekend hours, was open to all regardless of insurance status, was located in the inner city or was accessible by using public transport, and was attentive to waiting times. Among Latinas, having a doctor fluent in Spanish and from a similar cultural background was an additional priority.

Within the category of comprehensiveness, the most frequently mentioned themes were the availability of multiple services at one site, presence of an intake procedure that recognized one's needs, coordination of medical and social services on-site, and the availability of counseling and treatment for emotional and mental health concerns. Sample quotes from the focus group transcripts, organized within the 6 content areas, are presented in Table 3.

## DISCUSSION

Eighty-six percent of participants' comments fit into 1 of 3 content areas: physician-patient relationship, accessibility, and comprehensiveness. The breadth and depth<sup>9</sup> of physician-patient interactions in primary care make its relationship unique. Heavy emphasis on interactions with their primary care physicians (one third of all comments) supports other authors' statements about vulnerable patients placing a special emphasis on this relationship.<sup>15,16</sup> Underinsured people lacking access to alternate providers have a heightened reliance on a physician's competence, skills, and good will.<sup>15</sup> Having a sense that their physician had concern and respect for the patient was the most frequently mentioned priority in the focus groups. When working with low-income minority or immigrant patients, physicians might want to be especially sensitive to their voice, tone, and posture to communicate a sense of respect and concern for patients who may already feel vulnerable. It appears that the category of physician-patient relationship is vital to the conceptual framework of primary care for these low-income women, and it may be a link in the chain without which the other features (continuity, comprehensiveness, coordination, accessibility, accountability) cannot function optimally.

Accessibility was also a clear priority for these women. Twenty-two of the 24 women in this study were uninsured. This may explain why a large percentage of their comments (37.4%) fell into this category. Even though these uninsured women were receiving medical care in community clinics, issues of access (particularly of organizational access) were still foremost in their minds. This may be due to previous obstacles encountered in obtaining care or to deficiencies or strengths perceived in their current systems. Juxtaposed against the reality of increasing underinsurance for even basic access to services, this underscores a serious and worsening problem of unmet health care delivery needs. This emphasis on accessibility demonstrates the need to improve both

the financing and organization of the primary care safety net.

The themes most frequently raised with respect to comprehensiveness highlight how the needs of economically vulnerable people may differ from those who are financially secure. For example, previous research shows that poor women have a higher prevalence of mood disorders than the general population,<sup>18</sup> and most would prefer to be treated for these in the primary care setting,<sup>19,21</sup> since they often do not have the choice of going directly to specialty mental health services. This supports the provision of basic mental health care for the more common and treatable mood and anxiety disorders in the primary care setting. Stronger ties between primary care and certain specialty services may be needed to ensure such comprehensiveness.

A comparison of these participants' priorities with those of the general population in the literature yields similarities and differences. Priorities vary with sociodemographic characteristics<sup>22</sup>: younger patients valued coordination of care and technical proficiency most, while older patients ranked continuity of care and comprehensiveness highest.<sup>23</sup> Older patients placed more emphasis on cost issues<sup>15,23</sup> and on attributes of accountability.<sup>17,24-25</sup> Differences have also been shown by health status: Patients with a chronic illness preferred continuity over other features.<sup>23</sup> In the general population, accessibility, coordination, information, communication, education, respect for patients' values and expressed needs, and emotional support are the greatest concerns.<sup>26</sup> Population differences in priorities demonstrate that primary care systems must be tailored to the specific needs and priorities of the populations served.

Comparison of our study's findings with those of the general population raises the issue of what these low-income women were not saying. For example, issues of accountability were infrequently mentioned. This may reflect the participants' greater concerns with having accessible care. Also continuity of care, while accounting for only 3.7% of comments, was tied to other specific attributes considered important by these women. For example, attributes of the physician-patient relationship, such as communication, are directly tied to the presence of an ongoing relationship with a physician over time. Furthermore, given the dependence of economically vulnerable persons on their primary care physician for access to services and the important role this physician has in coordinating their care, continuity seems especially important.<sup>15</sup>

## Limitations

Several limitations should be considered in interpreting these findings. We investigated the research questions in this exploratory study by using focus groups and qualitative analysis. Such methods, if

mindful of established standards,<sup>12</sup> can yield well-grounded and detailed data. However, we cannot determine their generalizability. Further work to rank women's priorities for primary care and to tie them to utilization and health outcomes will be pursued in the future through a population-based study. Also, qualitative data are subject to researcher bias. Our use of 3 independent raters and our careful attention to coding using established methods<sup>12</sup> should have minimized this limitation.

## CONCLUSIONS

Established frameworks for primary care, with the addition of the category of the physician-patient relationship, have qualitative (content) validity in this sample of low-income women; therefore, these content areas provide a useful language to discuss their health care delivery needs. The physician-patient relationship, accessibility, and comprehensiveness were the categories into which most of the women's specific priorities fell. Health systems that fail to address low-income women's specific needs may not adequately meet their clients' expectations for health care.

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JFP



# Are We Getting the Message Out to All?

## Health Information Sources and Ethnicity

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**Background:** Over 80% of the excess deaths in minority and economically disadvantaged populations are from diseases with preventable or controllable contributing factors. However, mainstream health education targeting behavior change often fails to reach minority populations.

**Objective:** To identify the health and cancer information sources used by a multi-ethnic population and to determine whether information sources differ by ethnic group, age, gender, and socioeconomic status.

**Methods:** A multilingual, random-digit dial telephone survey of 2462 Hispanic (Colombian, Dominican, Ecuadorian, and Puerto Rican) and black (Caribbean, Haitian, and U.S.-born) persons, aged 18–80 years, from a population-based quota sample, New York City, 1992.

**Results:** All ethnic and age groups cited a health professional as the most common source of health information (40% overall). The next most commonly cited sources overall were: television (21%), hospitals or doctor's offices (18%), books (17%), magazines (15%), brochures/pamphlets (11%), and radio (8%). Responses on sources of cancer information followed a similar pattern. Black subgroups were all significantly more likely than Hispanic subgroups to get their health information from a doctor or other health professional ( $p = 0.001$ ). Use of the radio as a source of health information was highest among Haitians (20.8%) and Colombians (12.5%), and lowest among U.S.-born blacks (4.2%) ( $p = 0.001$ ), but there was no difference in the use of television. Among immigrants, as the proportion of life spent in mainland U.S. rose, increasing percentages cited magazines ( $p = 0.001$ ) and decreasing percentages cited radio ( $p = 0.025$ ) as a health information source. Less educated persons and more recent immigrants were most likely to report inability to get health information ( $p = 0.001$ ).

**Conclusions:** Given the variation in sources of health and cancer information, identification of those most commonly used is important to health educators' and public health practitioners' efforts to target hard-to-reach ethnic minorities.

**Medical Subject Headings (MeSH):** information dissemination, health behavior, ethnicity, Hispanic Americans, information distribution, communication (Am J Prev Med 1999; 17(3):198–202) © 1999 American Journal of Preventive Medicine

### Introduction

Minority and economically disadvantaged communities lag behind the U.S. population overall on virtually all indicators of health status. Over 80% of excess deaths in these populations are from diseases with preventable or controllable contributing factors: cancer, heart disease and stroke, homicide and unintentional injuries, infant mortality, diabetes, and chemical (primarily alcohol) abuse.<sup>1</sup> However,

mainstream health education targeting behavior change often fails to reach minority populations.<sup>1–3</sup>

While some data on the health information sources used by the majority population have been published,<sup>4–6</sup> little information is available on the sources of health information used most often by persons of color, especially within northeastern Hispanic and black communities. Prior work comparing non-Hispanic whites and southwestern Hispanics has shown ethnic-specific preferences for certain sources of health information.<sup>7–9</sup>

In addition, most studies on information sources focus on patients currently undergoing treatment for a specific disease<sup>10</sup> rather than on the general asymptomatic population.

The purpose of this report is (1) to identify the health information sources used by the ethnic groups

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accounting for the largest percentage of blacks and Hispanics in New York City and (2) to assess how ethnicity, age, gender, language, and socioeconomic status relate to differences in health information sources used.

## Methods

This study is part of a larger project assessing the general health and cancer-prevention needs of Caribbean, Haitian, and U.S.-born blacks, and Puerto Rican, Dominican, Colombian, and Ecuadorian Hispanics living in all 5 boroughs of New York City. These 7 populations compose the largest subgroups of blacks and Hispanics in New York City.<sup>11</sup> The majority (75%) of the sample were immigrants. Data were collected from May to October of 1992 by experienced multilingual interviewers using computer-assisted telephone interviews (CATI). The study used a quota sample to identify 50 men and 50 women from each racial/ethnic group (except for Haitians;  $n = 25$  per group because they were added after grant funding) in 4 age groups: 18–44 years, 45–54 years, 55–64 years, and 65–74 years for a total goal of 2600. Details on the survey and sampling methodology have been published elsewhere.<sup>12,13</sup>

Survey participants were asked in their language of preference (English, Spanish, or Creole) a previously validated,<sup>14</sup> open-ended question: "Where do you usually get your health information?" Interviewers had a long list of potential responses that could be checked if offered by the respondent. The potential responses included:

**People:** (doctor/health professional [i.e., clinician], family, friend, home country, other);

**Cancer organizations/programs:** (Cancer information services, National Cancer Institute, American Cancer Society (ACS), Telephone information—Public service or hot line, government agencies/program—unspecified, private organization/program—unspecified, other cancer organization/program—unspecified, health fairs/seminars);

**Non-cancer organizations/places:** (church/religious place, grocery store, hospital/doctor's office, school, library, workplace, union, other local organization, other national organization, HMO/GHI/HIP-Insurance company);

**Electronic media:** (radio, television [TV]);

**Printed Material:** (brochure/pamphlet, book, magazine, newspaper, medical journal, encyclopedia, other);

**Other:** (specify); and

**Unable to get information; None/Never looked/Don't know.**

Of those who responded positively to another item on whether they had sought cancer information in the past 5 years, a further question was asked, "When you were

seeking cancer information, where did you get it?" Potential responses that the interviewer could check, if offered by the respondent, were the same as above.

We report descriptive statistics on sources of health information used by black and Hispanic ethnic subgroups stratified by personal, demographic,<sup>13,15,16</sup> and socioeconomic characteristics. Stratified analyses and multivariate logistic regressions were done, using SAS (SAS Software, Cary, NC),<sup>17</sup> to assess whether use of clinician as information source (the most commonly cited response) differed significantly by ethnicity after controlling for insurance status, proportion of life on mainland U.S., and presence of a usual source of care.

## Results

The survey was completed by 2462 persons. The response rate for all calls made, including those to determine eligibility, was 62.3%. Among respondents qualifying for the survey on the basis of age and ethnicity, the refusal rate was 2.1%.

### Health Information Sources Cited by the Overall Sample

For all ethnic and age groups the highest proportion of respondents (31%–63%) volunteered that a doctor or health professional was a source of health information. The next most commonly cited sources of health information for the overall sample were: television (21%), hospitals or doctor's offices (18%), books (17%), magazines (15%), brochures/pamphlets (11%), and radio (8%). Differences by ethnicity are summarized in Table 1.

### Cancer Information Sources for the Overall Sample

Among the 1333 respondents (54% of the total sample) who had sought cancer information in the previous 5 years, the proportions using each type of cancer information source followed a similar pattern to the responses about health information in general (clinician 22%; hospital/doctor's office 15%; radio 6.1%; television 18.7%; brochure 16.8%; book 13.1%; magazine 15.2%; newspaper 9.3%). Cancer organizations/programs (CIS, NCI, ACS) were cited by  $\leq 1\%$  of respondents as sources from which cancer information was sought. Mention of the workplace (2.5%), schools (2.2%), churches/religious places (1%), libraries (1%), cancer organizations/programs ( $<1\%$ ), unions ( $<1\%$ ), insurance companies ( $<1\%$ ), home country ( $<1\%$ ), or grocery stores ( $<0.1\%$ ) as either a general health or a cancer information source was universally low.

**Table 1.** Health information source reported by ethnic groups, multi-ethnic sample, New York City, 1992\*

Source of Information	Total N = 2462 %	Colombian n = 329 %	Dominican n = 492 %	Ecuadorian n = 258 %	Puerto Rican n = 450 %	Caribbean n = 357 %	Haitian n = 168 %	U.S.-born Black n = 408 %	p
<b>People</b>									
Doctor/Health-Prof.	40.0	34.0	31.1	32.9	36.2	48.2	63.7	47.6	.001
Family	4.2	3.3	3.6	2.7	4.7	5.3	4.7	4.7	.664
Friend	3.9	2.7	3.7	1.5	4.7	4.8	4.8	4.9	.252
<b>Non-Cancer</b>									
<b>Organizations/Places</b>									
Hospital/Dr.'s Office	18.4	21.0	22.2	19.4	20.7	12.0	13.1	16.4	.001
School	2.2	2.7	2.6	2.7	0.7	2.0	5.4	1.2	.013
Workplace	2.5	0.3	2.2	1.6	2.7	5.0	2.4	2.7	.008
<b>Electronic Media</b>									
Radio	8.1	12.5	8.3	6.2	7.1	4.7	20.8	4.2	.001
Television	21.1	23.1	19.9	18.6	19.1	21.0	30.4	21.6	.065
<b>Printed Material</b>									
Brochure/Pamphlet	10.7	11.6	8.7	6.7	12.0	9.8	16.1	12.2	.030
Book	17.2	13.4	11.2	12.0	15.8	26.0	19.0	23.8	.001
Magazine	15.3	14.9	11.4	9.7	17.6	17.7	11.9	20.6	.001
Newspaper	9.5	6.1	9.6	6.6	10.7	9.5	8.3	13.0	.032
Medical Journal	4.8	0.9	3.0	3.1	3.8	8.7	5.4	8.8	.001
<b>Other</b>									
Unable to get info.	2.8	3.6	4.7	5.0	1.1	2.2	4.8	0.0	.001
None/Never looked	3.7	4.9	6.1	3.5	4.4	2.2	3.0	1.0	.002

\*Only information sources reported by  $\geq 2\%$  of the sample are listed in this table. (N = 2462) (Responses to open-ended question, "Where do you usually get your health information?")

### Role of Social and Demographic Factors on use of Health Information Sources

**Age.** There was a linear increase in percentage citing the doctor/health professional as a source of health information with increasing age (18–44 years: 33.3%; 45–54 years: 38.2%; 55–64 years: 44.2%; 65 + years: 52.1%  $p = 0.001$ ). There was a decrease in reports of use of television as an information source with increasing age ( $p = 0.001$ ). Citing magazines or newspapers as a health information source was higher in the two younger age groups (19.3% and 11.2%, respectively) and decreased in the older age groups (10.8% and 6.3%;  $p = 0.001$  and  $p = 0.033$ , respectively) (data not shown).

**Gender.** For all ethnic groups combined, females were more likely than males to get their health information from a doctor/health professional (42.5% versus 36.7%;  $p = 0.003$ ). Males were more likely than females to get their health information from newspapers (12.9% versus 7.0%;  $p = 0.001$ , respectively). Similar and significant differences were found by gender for sources of cancer information (data not shown).

**Educational and immigration status.** Increasing education was negatively associated with citing hospitals as a source of health information. ( $p = 0.002$ ) Television was cited as an information source among a larger percentage of more highly educated persons (high school graduates or higher) (24.3%) than less educated persons (8 years or less) (14.9%) ( $p = 0.001$ ). Also, less

educated persons and more recent immigrants were more likely to report being unable to get health information ( $p = 0.001$ ). As proportion of life spent in the mainland U.S. increased, higher percentages cited magazines as a source of health information ( $p = 0.001$ ) and conversely, lower proportions cited radio as a source of health information ( $p = 0.025$ ) (data not shown).

**Insurance.** Since insurance is the most powerful predictor of access to the health care system, it was not surprising that the highest proportion of persons saying that they usually get their health information from a doctor/health professional was privately insured (55.4% private, 28.0% public, and 16.5% uninsured  $p = 0.001$ ). Among the insured, similar proportions cited the doctor/health professional as a usual source of health information (45.2% for private and 42.8% for public); whereas only 27.9% of uninsured persons cited the doctor/health professional as a usual information source ( $p = 0.001$ ). Use of print materials as information sources (brochures/pamphlets, books, magazines, and newspaper) was highest among the privately insured (data not shown).

**Ethnicity.** When the Hispanic groups' use of television as a health information source was stratified by a language-based acculturation measure, ethnic differences did emerge. Among less acculturated Hispanics (those who used Spanish more than English with family, friends, co-workers, and in media consump-

tion), 23% of Colombians, 18% of Dominicans, 19% of Ecuadorians versus only 11% of Puerto Ricans reported using TV as a source of health information ( $p = 0.04$ ). Among the more acculturated Hispanic groups, there were no significant differences in TV use. For all other forms of media there were no significant ethnic differences within each mode's use as health information source when stratified by acculturation (data not shown).

Multivariate logistic regression models, in which use of a clinician as information source was the dependent variable, were done to assess whether ethnic subgroup was a significant predictor after controlling for insurance status, proportion of life in the U.S., and presence of a usual source of care.<sup>12,13,18</sup> Compared to U.S.-born blacks (reference group), Dominicans and Puerto Ricans were significantly less likely (OR = 0.731, 95% CI: 0.55–0.96; OR = 0.742, 95% CI: 0.57–0.96, respectively) and Caribbeans and Haitians were significantly more likely (OR = 1.44, 95% CI: 1.1–1.9; OR = 3.0, 95% CI: 2.1–4.4, respectively) to use a clinician as information source. Thus, ethnic subgroup, insurance, and presence of a usual source of care remained significant predictors of the use of a clinician as a health information source (data not shown).

## Conclusions

This study found wide variation by ethnicity, age, gender, socioeconomic status, insurance, and the proportion of life spent in the U.S. in the reported sources of health and cancer information.

In research on the perceived credibility<sup>7</sup> and frequency<sup>10,19–21</sup> of information sources among Mexican-American Hispanics and non-Hispanics whites, physicians were reported as most credible and most frequently used.<sup>7,10,19–21</sup> Given good evidence that clinicians can change some patient behaviors through simple counseling interventions in the primary care setting,<sup>21–24</sup> it is reassuring to find that this was the usual source of health information cited by the largest percentage of respondents. This also highlights the importance of patient-provider communication in information dissemination to higher-risk groups.

In terms of comparisons between the non-Hispanic white population and persons of color, National Health Interview Survey data indicate that African Americans are more likely than whites to receive some types of health information (e.g., HIV information) by reading brochures or listening to the radio.<sup>25</sup> In other studies of HIV information, urban African Americans and Hispanics were more likely to rely on mass media sources (e.g., television) whereas whites were more likely to receive information through targeted small media (e.g., brochures),<sup>26</sup> newspapers, or magazines.<sup>27</sup> Use of English print media is likely related to language preference and acculturation level. In this study, respon-

dents were not asked to specify whether the forms of print media used were in English or Spanish, so associations between language skills and media language consumption could not be ascertained.

Health communication efforts through mass media have been shown to be most effective when combined with community-based programs.<sup>28</sup> In this study, less educated ( $\leq 8$  years of school) and less acculturated persons had difficulty obtaining health information. This difficulty may have been due to low literacy levels, poorer access to media and health professionals, preoccupation among recent immigrants with socioeconomic survival, or lack of knowledge of where to go for health information. Traditional media sources may be less promising avenues for reaching higher-risk persons. More grassroots community-based efforts (e.g., use of lay health workers or targeting barrios) may be necessary to effectively target these groups.

There is too little literature on health information sources in minority groups to verify whether changes in information campaigns have occurred since these data were collected. At the very least, these data serve as a baseline of health information sources used in this multi-ethnic community, and can help inform strategies to target these populations. One source of information used with increasing frequency since 1992 is the Internet; however, its accessibility to this population is unclear. Other methodologic limitations in these data have been described elsewhere.<sup>12,13</sup>

This study described health information sources used by hard-to-reach members of these ethnic groups. Further study of the effectiveness of these information sources in promoting behavior change in these communities is needed. Given that these hard-to-reach populations have rates of preventable deaths in excess of the majority population, renewed efforts to provide culturally appropriate and educationally tailored messages and materials to these populations must be given serious consideration.

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American Society of Preventive Oncology  
24th Annual Meeting -- March 5-7, 2000  
Bethesda, Maryland

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January 5, 2000

Ann O'Malley  
Georgetown University Medical Center  
Lombardi Cancer Center  
2233 Wisconsin Ave., N.W., Ste 440  
Washington, DC 20007

Dear Dr. O'Malley:


Congratulations! Your abstract, No. 24-33, has been accepted for presentation as a poster at the 24th Annual Meeting of the American Society of Preventive Oncology in Bethesda, MD, March 5-7, 2000.

The poster session is scheduled for Monday, March 6, from 6:00 pm to 7:30 pm. The room will be ready for you to set up your poster at noon on that day, so you should not have to miss any of the program. You will have a 4' x 4' space in which to display your work.

Please fill in the bottom portion of this letter and fax it back to me at (608) 263-4497 as confirmation of your participation. Please let me know by January 15, 2000, if you will be displaying your work at the poster session.

We look forward to your participation at the ASPO Meeting. If you have not already registered to attend the meeting, you may get that form from the website [www.aspo.org](http://www.aspo.org), or feel free to give me a call at (608) 263-6809. To reserve your hotel accommodations, call the Hyatt Regency Bethesda at (301) 657-1234, and be sure to tell them you are with ASPO.

Sincerely,



Judy Bowser for E. Robert Greenberg, MD  
2000 Program Chair

Enclosure: Poster Guidelines

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I will   P   /will not        present my abstract, No. 24-33  
at the ASPO Meeting in March.

# AMERICAN SOCIETY OF PREVENTIVE ONCOLOGY - ABSTRACT FORM

For Submission of Presented Papers at the 24<sup>th</sup> Annual Meeting in Bethesda, Maryland, March 5-7, 2000.

An abstract, consisting of 150-200 words, MUST BE TYPED in the box below. Title should be brief and clearly state content of paper. Please list last names and first initials of co-authors. The body of the abstract should be organized as follows: 1. Purpose of study (one sentence if possible). 2. Simple statement of methods. 3. Summary of results (adequate to support conclusion). 4. Statement of conclusions. (Do not use phrases such as "The results will be discussed.") 5. Authors must use 12-point type, and no illustrations are permitted within abstracts. Space has been allocated to publish the top-ranked abstracts in the February '00 issue of Cancer Epidemiology, Biomarkers and Prevention. Do not reduce the abstract to "make it fit", as it will be reduced for reproduction in the journal. Do not type across the "borders" of the abstract box or the line will show up in the program or CEBP, if chosen for publication.

I would like to present this abstract as:

- ☒ an oral presentation (1<sup>st</sup> choice)  
☐ a poster  
☒ either orally or as a poster

Please mark (X) the ONE category in which you wish to have this abstract considered for either oral or poster presentation:

- ☐ Cancer Epidemiology  
☒ Cancer Screening  
☐ Chemoprevention  
☐ Behavioral Science  
☐ Biomarkers  
☐ Genetics  
☐ Nutrition  
☐ Tobacco

Categories may be combined for oral paper sessions depending upon number of submittals in each category.

Oral Presentations will be limited to 15 minutes. 35mm and overhead projectors will be available for all sessions.

Poster Presentations: Each abstract accepted as a poster will be assigned a 4' x 4' space in which to display the complete presentation.

The submittal MUST consist of:

- 1) the original copy, typed directly on the Abstract Form;
- 2) 16 photocopies of the abstract;
- 3) the completed acknowledgment card;
- 4) 2 stamped, self-addressed #10 envelopes

**FAX Copies are Unacceptable!**

*This form may be duplicated, or additional copy may be downloaded from the website.*

Mail completed packet to:

Amer. Society of Preventive Oncology  
 Attn: Judy Bowser  
 1300 University Ave., Suite 7-C  
 Madison, WI 53706

Type abstract below. Stay within borders.

## **Primary Care and Receipt of Regular Breast, Cervical and Colorectal Cancer Screening in Low-Income Women.**

O'Malley AS, Forrest CF, Mandelblatt J. Georgetown University Medical Center, Lombardi Cancer Center.

**Purpose:** Despite lower incidence rates for many cancers, low-income minority women have higher rates of cancer mortality, than white and more economically advantaged women do. To examine the specific features of primary care that promote regular use of breast, cervical and colorectal cancer screening for low-income, urban, minority women.

**Methods:** A bilingual telephone (CATI) survey of a population-based sample of 600 low-income women in Washington, D.C. to be conducted Dec, 1999- Jan, 2000.

**Results:** Preliminary data have shown that low-income minority women who had a usual source of care, and continuity with a clinician at that site, were significantly more likely to have "ever" and "recently" received pap smears (OR=2.63.  $p \leq .01$ ; OR=2.00  $p \leq .05$ ), clinical breast exams (OR=2.83.  $p \leq .01$ ; OR=2.65.  $p \leq .01$ ) and mammograms (OR=2.30  $p \leq .05$ ; 1.40) respectively, than were women without a usual source of care. Data from focus groups show that low-income minority women find particular features of primary care (*accessibility, patient-provider relationship, and comprehensiveness*) especially important. We will conduct a population-based survey to further assess which particular features of primary care were most important to low-income, minority women; and, whether attainment of those features was associated with receipt of regular breast, cervical and colorectal cancer screening.

**Conclusions:** Survey findings will guide a future intervention that modifies one or more important features of primary care in order to increase breast, cervical, and colorectal cancer screening in community primary care settings.

TYPE name, address, and telephone number of AUTHOR WHO WILL BE PRESENTING the work at

ASPO:

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ABSTRACT DEADLINE: OCTOBER 22, 1999.

Additional copies may be downloaded from the website: [www.aspo.org](http://www.aspo.org)



PRIMARY CARE & RECEIPT OF REGULAR BREAST  
CANCER SCREENING IN LOW-INCOME WOMEN

O'Malley AS<sup>1</sup>, Forrest CF<sup>2</sup>, Mandelblatt J<sup>1</sup>.

<sup>1</sup>Georgetown University Medical Center,  
Lombardi Cancer Center. <sup>2</sup> Johns Hopkins  
School of Hygiene and Public Health.

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**Purpose:** Despite lower incidence rates for breast cancer, low-income and minority women have higher rates of breast cancer mortality than white and more economically advantaged women do. This study examines the specific features of primary care which promote early detection of breast cancer for low-income, urban women.

**Methods:** A bilingual telephone survey of a population-based sample of 600 low-income women in Washington, D.C. to be conducted from January- March, 2000.

**Results:** Earlier data collected in another low-income, minority (NYC) population have revealed that low-income women who had a usual source of care, and continuity with a clinician at that source of care were significantly more likely to have "ever" and "recently" received clinical breast exams (OR=2.83.  $p \leq .01$ ; OR=2.65.  $p \leq .01$ ) and mammograms (OR=2.30  $p \leq .05$ ; 1.40) respectively, than were women without a usual source of care. Data from focus groups in this Washington, D.C. sample showed that low-income minority women found particular features of primary care (*accessibility, patient-provider relationship, and comprehensiveness*) especially important. This Washington, D.C. population-based survey will assess empirically whether those same features of primary care were most highly valued by low-income, minority women; and, whether attainment of those features was associated with receipt of regular breast cancer screening.

**Conclusions:** Survey findings will guide a future intervention that modifies one or more important features of primary care in order to increase breast cancer screening in community primary care settings.

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